PICTURING LIFE-STORIES IN A BIOMEDICAL SETTING: A PHENOMENOLOGICAL ANALYSIS OF NEONATAL END-OF-LIFE PHOTOGRAPHY

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ABSTRACT

This dissertation explores End-of-Life (EOL) photography, a common practice in North American hospitals whereby nurses facilitate photography for families around the death of their newborn. It is based on a qualitative study involving semi-structured interviews with 10 parents bereaved by a neonatal death in the last five years, who all participated in EOL photography in the same Canadian neonatal intensive care unit (NICU). The focusing research question asked how parents experience this photography within the NICU setting and in their lives beyond the hospital. The study's methodology combines the existential phenomenology of Maurice Merleau-Ponty and the critical theory of Michel Foucault to consider the intersections of lived experience, media technologies and the material structures of power/knowledge. The method is modeled on an interpretive phenomenological analysis approach involving an embodied hermeneutic and integrating photo elicitation, as the participants were invited to bring their EOL photographs to the interviews. The dissertation situates EOL photography within the contemporary NICU, revealing the practice as an experience of *living relationships* between nurses, parents and newborns in the biomedical setting. It considers how the move from film to digital photography developed the practice from "memento-making" to collaborative "story-telling." New opportunities to construct the newborn's life-story is shown to be integral to the parents' knowing their newborn in life and healing from their death, yet opens complex questions around sharing this life-story within the families' social sphere. The dissertation reflects on these experiences in the context of a broader sociocultural ambiguity around death-in-birth, connecting EOL

photography with the politics of biomedical reproduction and end-of-life. The dissertation concludes by conceptualizing EOL photography as a practice of *palliative space-time*, which works towards presence, proximity, attention, and care into end-of-life in a biomedical setting.

DEDICATION

For Evi, Graydon, Little J, Jaxson, Little P, Ryder, Stella, Little S, and Little S.M.,

who I did not have the opportunity to meet but who I will never forget.

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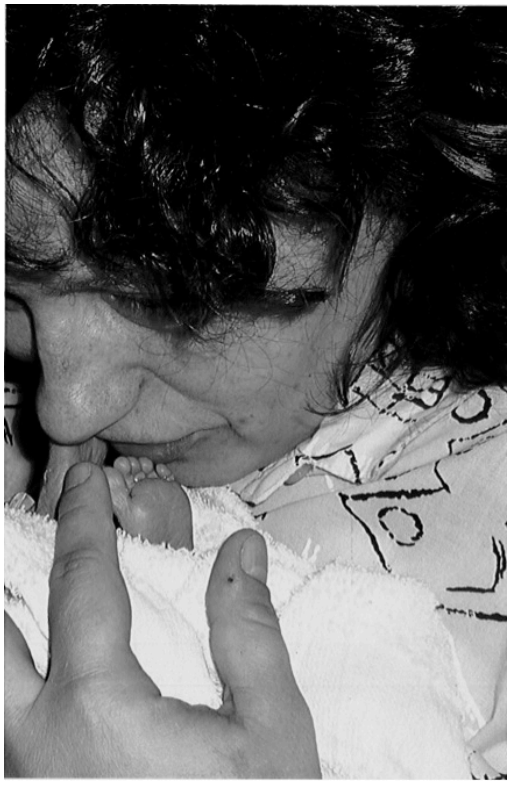

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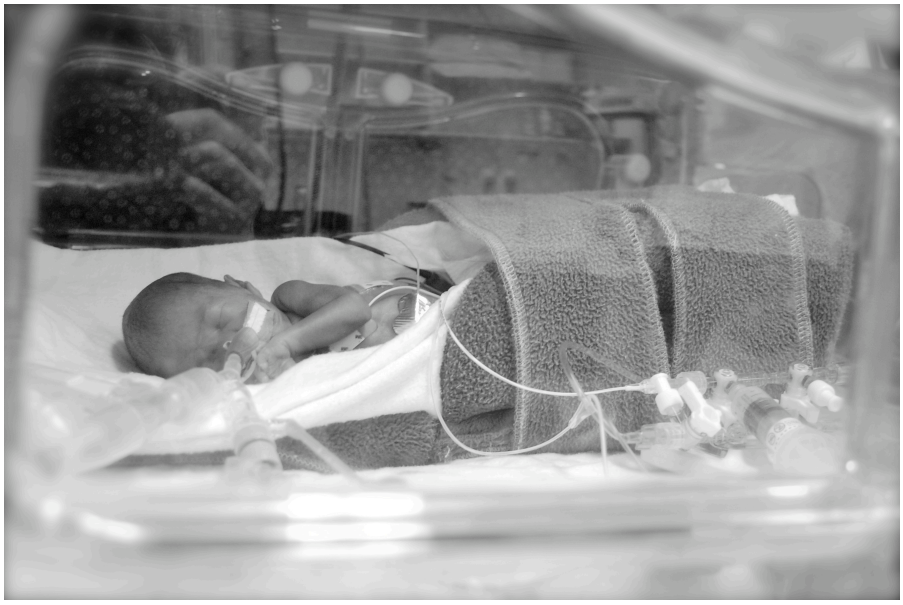

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1. INTRODUCTION

Three years ago, a friend was telling me about her work as a registered midwife in a Canadian city. Recent to our conversation, one of her clients had experienced a loss in a late term pregnancy. After a birth in hospital care, the mother and father spent some time holding their newborn until the baby took his or her last breaths. After the baby had died, my friend explained, a nurse gently placed the body on a blanket, dressed the baby in a little knit hat, and creatively arranged teddy bears and special mementos around the newborn. Then, the nurse took a camera that belonged to the hospital unit and photographed the baby in the same portrait style one might have done in a studio. These post-mortem photos were to be given to the bereaved parents. In imagining photography in these birth and death moments, I was overwhelmed both with compassion for the parents and empathy for the nurse, who at that moment was responsible for taking an exceedingly profound picture. As someone who has worked professionally as a photographer, I can recall the emotional moments that can occur when you look at someone through a lens with complete attention and intention. Even in the monumentally lighter task of documenting something like a wedding day, I have been keenly aware of the sensitive relationship that is established between myself and my photographic subjects, both intimate yet mediated by the glass, plastic and electronic parts that make up the camera in front of my eyes. What, then, must the experience of this photography be like? This is the question that struck me as immensely important and inspired me to pursue the research that constitutes this dissertation.

The photography my friend had described is usually termed 'bereavement photography,' or 'neonatal bereavement photography,' since it is most often practiced in hospital-based neonatal care, more so than in other pediatric or adult medicine.[1] I had been using this terminology early in my research, but have come to the term End-of-Life Photography (herein EOL photography). I use this language to acknowledge the ways in which the photography extends across a process that care-providers and families experience together around the life and death of a newborn—a process unfolding in duration of time, more than an isolated moment. While the term "bereavement photography" attaches the picture-taking to mourning that follows a loss, my findings consistently reveal the photography as a gesture made towards celebrating the beginning-of-life; the reality of a newborn death is that these beginnings and endings merge in a threshold across birth and death, which is a complexity central to EOL photography as both a media practice and a clinical practice.

EOL photography was introduced into neonatal and obstetric care in many North American hospitals throughout the late 1970s and 1980s as part of a broader development of bereavement support practices for parents who had experienced any variety of reproductive losses.[2] The photography is written about in nursing literature as an opportunity to create a memento for the parents to take home with them after their

[1] "Neonatal" is a clinical classification varying in national contexts. This dissertation uses Health Canada's definition of "neonatal," which aligns with the World Health Organization's definition, being a newborn in "the first 28 days of life": http://www.who.int/topics/infant_newborn/en/ Occasionally I use the term "perinatal," which is another clinical classification including the period before and after birth.

[2] My initial research suggests this was happening in some Western European countries as well, but my research focuses on the training and research that took place in North American hospitals, and my fieldwork looks at the Canadian context specifically.

child has died. The kinds of images that are taken include details such as tiny hands and feet, special moments such as the baby opening his or her eyes, the parents holding their newborn, and often siblings together with their newborn brother or sister. In hospital units that handle labour and birth, the photography can be offered when a baby is born still or when a critically ill baby is delivered alive but does not undergo life-sustaining measures. In units that do not handle labour and birth but offer tertiary care, the photography can be offered throughout the newborn's life in the hospital, around the withdrawal of life-sustaining technology and/or immediately after the baby dies. My research is focused on the latter, specifically looking at the use of EOL photography in a neonatal intensive care unit (NICU), in which critically ill newborns are transferred after birth for specialized care. While obviously many newborns who enter the NICU leave in sustainable health after receiving treatment, my research focuses on families whose newborns lived in the NICU for anywhere from a few hours, days, weeks or months, but unfortunately died in the NICU or at home in the family's care shortly after treatment was discontinued.

In the first few decades that EOL photography was developed as a practice, film cameras were made available in hospital units for nurses to use, usually providing no more than one roll of 12 frames per family. As digital technology developed throughout the early-1990s onward, digital cameras and memory cards have allowed nurses to take many more photos for parents with much more ease and affordability. Additionally, as digital cameras and accessories have become more affordable and easy to use today, an increasing number of parents themselves bring cameras into the hospital. The improved

quality of cellphone cameras has also meant the majority of parents are (even if inadvertently) carrying cameras at almost all times. Because the NICU is such a unique space and the newborns in its care are all in critical condition, the accessibility of camera equipment does not translate directly to an immediate comfort in taking photos in these situations, as my research suggests. It does mean, however, that studying EOL photography in a contemporary context requires an eye on the ways in which this practice is no longer solely carried out by nurses or other hospital staff, such as the case in its earlier form. EOL photography today is a collaborative process between parents and care-providers, even if the care-providers often take on the more dominant role of introducing and facilitating photography within the critical care setting.

In addition to the nurses and families taking photos, EOL photography can also involve the hospital arranging for a professional photographer to come in for a sitting with the families, as it did for some of my participants. In the early 2000s, *Now I Lay Me Down To Sleep* was established in the U.S. as an organization that connects hospitals with professional photographers who volunteer their services to provide families with quality family portraits.[3] With chapters in at least 40 countries, including Canada, *Now I Lay* is one of the major "bereavement" photography organizations to which Canadian hospitals turn when they have a family in their care interested in having professional photographs taken, though other organizations and/or independent photographers now offer these volunteer services as well.

[3] Source: https://www.nowilaymedowntosleep.org/about/mission-and-history/

1.1 Overview of this Research

This dissertation is based on a qualitative study into how parents experience EOL photography as a media practice and their EOL photographs as cultural objects. The phenomenological study was completed through a Canadian NICU, involving semi-structured interviews with 10 parents (four fathers and six mothers) who had all experienced a newborn death in this NICU within the last five years and had photos taken by nurses, themselves, and/or professional photographers.[4] After approval from both York University's Office of Research Ethics and my research setting's Research Ethics Board, I invited people to participate in the study through follow-up from the Palliative Care and Bereavement Coordinator (herein "Coordinator") at the hospital and the NICU bereavement newsletter, which is sent out to all families over the first year after their loss. This dissertation reports the study's major findings, intersecting them with concepts and insights from within communication studies, cultural studies, feminist studies, health studies, and science and technology studies.

The focusing question of my fieldwork asked how parents experience EOL photography in the NICU and as part of their life beyond the hospital up until the time of my interview with them. Interview questions and subsequent discussions related to

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[4] All interviews were completed between February 2013 and April 2013.

the parents' experiences having pictures taken by the nurses, themselves, family, or professional photographers, as well as their experiences with the photos in their daily life and environments. The focusing research question, interview questions and analysis of language, themes, narratives, and embodied responses in the interviews were all informed by an Interpretive Phenomenological Analysis (IPA) approach to qualitative research (Benner, 1994; Smith, Harré & VanLangenhove, 1995; Smith, Flowers & Larkin, 2009), which I take as a starting point for developing phenomenological research more so than a coherent method in itself. I provide more detail on my study's method and methodology in Chapter 2 and 3, but here will clarify that I am drawing specifically on the phenomenological philosophy of Maurice Merleau-Ponty (1962; 1964; 1968) to shape my analysis within what I would term an embodied-hermeneutic, focused on how participants interpret their own lived experiences as corporeal subjects.

I have assembled a methodological framework that grasps phenomena through two main lenses, melding method and theory in a productive union rather than an obfuscating duality: Merleau-Ponty's existential phenomenology and Michel Foucault's power/knowledge. I borrow conceptual tools from both thinkers to analyze how lived experiences are produced by but also exceed the system of discourses, procedures, spaces, temporalities, techniques, and technologies that constitute an "apparatus" (Agemben, 2009)—in this case, the apparatus of biomedical critical care within which my participants experienced the life and death of their newborns as neonatal patients. On one hand I appreciate Diana Coole's (2010) assessment that "The aim of existential phenomenology as Merleau-Ponty understood it is to return to lived experience before it

is written over and objectified by theory" (p. 93); however, my own aim is to think and write in a way that does not see theory as an obstacle to lived experience, but as the same process of meaning-making and speech that is "one's position in the world" (Merleau-Ponty, 1962). In other words, my fieldwork is the heart of this project—the muscle moving both the experiential findings *and* the theory through a vascular network of related histories, technologies, desires, and struggles as one substance.

As I detail more extensively in Chapter 2, I have identified three major lacunae in the sociocultural understanding of EOL photography that the findings in this dissertation address. Coming from a background in visual culture, I figure these lacunae in terms of (in)visibilities, meaning the way in which the photography has been made both visible and invisible, neither entirely present nor entirely hidden. The first (in)visibility is the way in which EOL photography has been understood within clinical fields such as nursing, midwifery and psychology. Much of this work approaches the photography as one of many "interventions" hospitals include in their neonatal or perinatal bereavement support services. The quantitative versions of this research are often survey-based and the qualitative versions tend to reduce parent "experience" to parent "satisfaction" with the photography as part of these services. What these clinical studies are not designed to provide, however, is a critical analysis of the hospital itself as the space within which the photography emerged. They do not question the epistemological specificities of biomedical reproduction, the spatio-temporal logics of critical care or the historical move from home to hospital of both birth and death across the twentieth century. In other words, they do not focus on the NICU specifically as the

space in which EOL photography is carried out, meaning the space that produces EOL's mediating logic and which families, newborns and care-providers inhabit, move through, shape, and are shaped by as photographic subjects.

The disciplinary angles of this existing clinical research also render the camera invisible, in that the practice of photography is not explored beyond the assumption that it is one among other memento-creation practices that produces memorabilia for the parents to take home and to help remember their newborn. While this memento function of EOL photography was present in my own findings as well, limiting research to these assumptions forecloses exploration of the photography itself as an embodied interaction that cannot be reduced to the symbolic objects it produces. The technological developments around film to digital photography and Web 2.0 applications that now circulate personal photographs are also not meaningfully addressed in terms of how they differently materialize desires, anxieties, relations, and the emotional labour care-providers take on in EOL photography as part of their clinical work. With the above gaps in mind, my research sheds light on parent experience of EOL photography within the NICU as a meaningful *space-time*, using this term to acknowledge the phenomenological significance of spatiality and temporality together in lived experience. My study also provides insight into the impact of digital photography through which both care-providers and parents are carrying out EOL photography today, highlighting how digital technologies have allowed care-providers and families to move EOL photography from memento-making to story-telling.

While critical work on photography from a communication or cultural studies

perspective would seem the ideal lens through which to examine EOL photography, my review reveals a significant absence of work on this topic within these fields; this is a particularly suspicious absence considering death is such a darling of photography theory. In the little work I did find, contemporary "bereavement photography" around the death of a newborn was presented as an extension of Victorian post-mortem custom by which loved ones were professionally photographed after death to provide families with a memory of the deceased. Conflating the Victorian practice with one carried out today returns us to the (in)visibility of the hospital, which is an integral aspect of contemporary EOL photography yet not a part of Victorian post-mortems that were often taken at home or in a photographer's studio, given the mobility of and proximity to dead bodies that accompanied death at home before death or birth moved to institutional spaces. My terming the photography "EOL" situates the practice in contemporary palliative care, which is technoscientifically managed, coordinated and administrated by hospital staff as opposed to the family at home, even if families are involved on some level. This institutional arrangement not only bears weight on families' experience within the NICU, but also influences their experiences beyond the hospital; because the life and death of their newborn occurs within a certain space-time distinct and in many ways isolated from the families' home and community, connecting their newborn to their wider social sphere is something parents have to actively cultivate, if or when desired. As my research suggests, photography plays a unique and central function in satiating this desire.

Lastly, this research has been guided by a concern for the sociocultural

(in)visibility of EOL photography. Despite the relative orthodoxy of EOL photography within hospital childbirth and neonatal care, it is clear that this photographic practice is not well known beyond communities of bereaved parents and care-providers. This reality was confirmed not only through an extensive literature review, but also through many interactions with people over my last four years of research. In almost any conversation I had about my work, even with clinicians in medical fields outside of obstetrics or neonatology, the same response was received: "I had no idea this photography existed!" Although colloquial, this response intimates the cultural politics of EOL photography, which can be related to the taboo of reproductive loss in Western society. Events such as miscarriages, stillborn babies and even neonatal deaths are rarely spoken about or publicly mourned the way other losses might be, as the subject of reproductive loss—the unborn subject—is ambiguous in Western society, made visible and celebrated in successful pregnancies, but dismissed and made unseen in pregnancy losses (Layne, 2000). Some have even argued the intensely political nature of unborn life has prevented reproductive loss from garnering attention within feminist scholarship, as the tie between abortion politics and fetal personhood means "[t]he appropriate position to adopt regarding pregnancy loss is a thorny one for feminists" (Layne, 1990, p. 83).

Like other forms of death-in-birth, neonatal death occurs across a threshold, a gestational period, duration into birth, clinically classified but philosophically blurred. The medical capacities of contemporary neonatology come into play here as it has facilitated the birth and survival of increasingly premature babies—babies that simply

would not have been brought into life or into sociocultural being in the Victorian era, even if late-term stillborn babies, newborns, infants or children were being photographed in death at the time. As discussed in Chapter 4, the "limit of viability" for unborn-now-born life has been extended by technoscientific intervention that can both detect medical or genetic issues early in-utero and can sustain life in pre-developed bodies until a treatment is determined or palliation is commenced. These are the material, clinical and sociocultural realities of EOL photography that cannot be overlooked in analysis of how families experience the photography. In other words, EOL photography ought to be considered in light of the biomedical nature of pregnancy and childbirth, which includes a certain ambiguity around death-in-birth. The intricacies of this photography, I propose, are fertile ground upon which communication and cultural scholars can seed broader inquiries. I take the near absence of any work on EOL photography in communication and cultural studies as indication that this ground, while rich, has yet to be cultivated. In addition to contributing original research on EOL photography to sociocultural fields, this project also offers relevant knowledge for healthcare and bereavement communities. While EOL photography remains a key component in the support most hospitals now provide for parents, it is not universal in North American healthcare. Its availability and scope depends largely on each hospital's culture, resources and familiarity with neonatal palliative care. This research can play a role in knowledge dissemination to both healthcare institutions that have not fully integrated photography into their bereavement support and those that have integrated it but remain interested in further developing best practices with parent experience in

mind. This is not to suggest, however, that my research was designed to argue the practical value of this photography, nor that I set out with pre-existing notions about what this photography is or what role it should play in grief work or bereavement support.

1.2 Dissertation Outline and Chapter Breakdown

Beginning with Chapter 2, I introduce this project as an intersection of sociocultural and clinical scholarship, involving fieldwork in a healthcare setting approached within a critical cultural communication framework. This chapter establishes the dissertation's theoretical and methodological interventions into and positions within existing research. In the first section I review healthcare literature and in the second section I review communication studies and cultural studies in the interest of identifying how EOL photography has appeared in relevant scholarly work to date. In the final section I outline my own challenges and contributions to the topic of EOL photography in the form of a phenomenological inquiry designed to respond to what is missing in the existing research.

Building on the methodological background I provide in Chapter 2, Chapter 3 is organized around two other foundations of research: epistemology and methods. In the first section I situate my knowledge production within a feminist epistemological framework. In the second section I explain how I have conceived the method as an Interpretive Phenomenological Analysis, also integrating the visual sociology technique of Photo Elicitation. The chapter provides an outline of the study's protocol and process

with a detailed description of the fieldwork research setting, operational definitions, design, objectives, procedure, protocol, data management, research ethics, etc.

Chapter 4 begins with an overview of the NICU specifically as the space within which EOL photography is carried out. I provide perspective into how neonatology was specialized and spatialized as a medical field developing throughout the mid to late twentieth-century, emerging out of an earlier socialization of reproduction and a medicalization of pregnancy and childbirth. Locating EOL photography within the biomedical specificities of the NICU brings the photography to light as a sociocultural practice embedded within material relations, countering its abstraction as a timeless or transcendent tradition. The second section of this chapter considers the way in which EOL photography came to be practiced in the NICU, pointing to the fact that bereavement support was not a facet of NICU care until a few decades after neonatology really developed as a specialized field. I frame the development of EOL photography in terms of an intervention into the NICU as a space that had distanced newborns from parents and parents from nurses. I consider the mediation of photography as the experience of "living relationships," moving EOL photography beyond "memento-making" to "story-telling," accompanying a move from film to digital photography.

The notion of "living relationships" is picked up again in Chapter 5 as I present findings on the spatio-temporal qualities of the environment that both shaped and were shaped by the participants' experiences. The first section of this chapter illustrates how parents entered and endured the NICU in a certain state of "shock" within which they

functioned as they were immersed into a regime of critical care for their newborn, and the last two sections turn to findings on how parents interpreted photography in this space beyond their initial reactions and entry into the NICU. These finding add further insights into the act of photography as it produces space-time through (inter)relations and (inter)actions. Based on my phenomenological analysis of parent responses, I propose a way of approaching EOL photography as materializing and mediating key relations in the NICU between parents and their newborns and between nurses and parents.

Moving beyond the NICU, Chapter 6 considers the parents' experiences with their EOL photos in their daily lives since the death of their newborn. In the first section I present three themes that emerged in the interviews: the photos as healing tools in what I term creative grief work, the 'thereness' of the photographs as material objects, and the immense value of the images that correlated with an intense fear of losing the digital image files. The second section discusses the complexity of and emotional labour around sharing EOL photos. While showing family and friends images from their newborn's life and death was key to parents' healing and acceptance of loss, it was also often a difficult thing to do for fear of rejection, hurtful comments, or making others sad or anxious.

Chapter 7 provides an overview of the findings reported in this dissertation. The chapter explains contemporary EOL photography within the phenomenological dimensions of the living-body and the lifeworld, arguing that the photography counters biomedicine's abstraction and rationalization of life and death by drawing attention and

intention to the living body and dying body as part of a meaningful community. I conclude by conceptualizing EOL photography as fostering what I term *palliative space-time*, referring to the practice's intervention into the biomedical apparatus.

2. SITUATING THIS DISSERTATION: A THEORETICAL AND METHODOLOGICAL MAP

"Writing has nothing to do with signifying. It has to do with surveying, mapping, even realms that are yet to come." (Deleuze & Guattari, 1987, p. 5)

From the outset of this research, I have been made keenly aware of the way in which my work intersects the worlds of sociocultural and clinical scholarship. This intersection results from conducting sociocultural research within a healthcare setting on an object of study that is a creative (or at least vernacular) media practice carried out by and for families in ways that exceed the clinical purview of its environment. I have approached my own research as a critical cultural communication project (Ono, 2009), but understand that the ideas will cross borders into both friendly and unfriendly territories governed by various ways of knowing. Figuratively speaking, then, this chapter is intended to constitute the project's identification as it travels, even if through a chain of difference. The chapter does so by establishing the dissertation's theoretical and methodological interventions into and positions within existing research. In the first section below I review the way in which EOL photography has been researched within healthcare and in the second section I consider the near absence of EOL photography in communication studies and cultural studies, even in work that could be called 'photography theory' more narrowly. From there I outline my own challenges and contributions to existing research, situating my theoretical and methodological work within the fields through which it travels.

2.1. EOL Photography as an Object of Study in Healthcare Literature

What first struck me about EOL photography was the seeming disjuncture between the medical setting in which it was carried out and the distinctly non-medical nature of the images themselves. As can be seen from the images reproduced in this dissertation, EOL photography draws from the aesthetic of contemporary family photography, which typically includes the capture of both posed portraiture and stylized but candid interaction shots. While EOL photography shares some of the same technical requirements as other medical photography, such as competent lighting for example, EOL photos have a more creative and personal sensibility than the didactic images typical of medical images. Taking on the role of photographer in their daily work, neonatal nurses (and occasionally counsellors, chaplains, and other medical staff) are often given training materials for taking the best pictures. Amongst the first and most well-known sources for these guidelines is *When a Baby Dies: A Handbook for Healing and Helping* (1986), developed as part of the Resolve Through Sharing program, which to this day provides workshops and other publications for bereavement support professionals. As we see in this excerpt, from *When a Baby Dies*, the handbook includes technical and creative tips:

> When photographs are taken, a ribbon or hat can be strategically placed to cover defects. Different views should be taken, including close-ups for special features (e.g., hands). At least one photograph should be taken of the baby nude so that parents have a chance to see the baby that way, should they wish to do so. Pictures that include a pretty blanket, baby toy, or fresh or silk flowers provide better

photographic memories. Parents also may appreciate a family photo which includes surviving siblings. (Limbo & Wheeler, p. 96)

While it is inaccurate to categorize EOL photography as 'medical photography,' neither can we claim there is no clinical aspect at play. When we trace the development of EOL photography in healthcare, we find it was indeed conceived as a clinical intervention, not as treatment for the newborn patient but for the parents exhibiting symptoms of grief around the death of their newborn. The psychological response to the death of neonates, particularly those who were born extremely premature, was not always recognized or addressed by caregivers in western institutions, despite the fact that the majority of births were happening in hospitals by the 1950s in both Canada (Mitchinson, 2002) and the U.S. (Oakley, 1984). Across the 1970s and 1980s, however, grief response to a variety of reproductive losses emerged as a significant object of study within clinical research. Medical literature, and the "psychological sciences" (Rose, 1988) in particular, posited a newly identified form of loss termed "perinatal bereavement" as a pervasive yet silenced phenomenon in hospitals (Zabourek & Jensen, 1973; Furman, 1978; Peppers & Knapp, 1980; Forrest, 1982; Borg & Lasker, 1989; Hughes & Page-Lieberman, 1989). Perinatal means *around* birth, so perinatal bereavement could mean anything from a baby who is born still, to ectopic pregnancy, to abortion, therapeutic termination, to newborn death. Research concluded that parents were not acknowledged as bereaved, nor were they supported through their bereavement within the medical institutions responsible for their birthing experiences. Lasker and Toedter suggest

> [f]or many years the typical hospital management of patients who experienced a pregnancy loss—spontaneous abortion, ectopic pregnancy, stillbirth, or neonatal death—was either to try to "protect" the parents from grief or to ignore the event altogether. Babies were whisked away and disposed of without the parents having any opportunity to see or hold them, bereaved mothers were placed in rooms with the mothers of healthy newborns, and any mention of the loss was discouraged. (1994, pp. 41-42)

Much of the literature emerging in the late twentieth century focuses on the grief responses of mothers specifically, as we see in the seminal research by Peppers and Knapp published in *Motherhood & Mourning: Perinatal Death* (1980). One of the key contributions from this work is the finding that "all mothers experienced some degree of grief" (p. 19) despite the gestational age of the foetus at the time of loss. Using self-reporting from bereaved mothers and a 16-item scale, the authors conclude that mothers who had experienced late term losses (i.e. at least six months gestation) grieved for a longer duration compared to mothers who experienced early term losses, but the initial impact of grief had the same level of intensity throughout the sample (p. 19). While subsequent research both supports and counters Peppers and Knapp's findings regarding the impact of gestational age on grief response (see Kirkley-Best, 1981; Smith & Borgers, 1988; Dunn & Goldblach, 1989), overall the research of the day concluded that a variety of reproductive losses were grievable events for both mothers and fathers, even if in differing degrees and expressions between the parent genders (see Benfield, Lieb & Vollman 1978; Mandell, McAnulty & Reece, 1980; Goldblach, Toedter &

Lasker, 1991).

Accompanying the validation of grief was the identification of psychological stages, expressions and outcomes of perinatal bereavement (Leon, 1987; Peppers & Knapp, 1988; Toedter, Lasker & Alhadeff, 1988; Engler & Lasker, 2000). Clinicians and counsellors set out to develop interventions for supporting parents through their bereavement both in the hospital and ongoing, with the goal of resolving grief and avoiding "morbid grief reactions" (Cullberg, 1971). Specific to a Canadian context, Deborah Davidson's research in Ontario hospitals reveals "[t]he key actors involved in the development of the bereavement protocols include primarily hospital caregivers—nurses, chaplains, social workers, and physicians—and also health care advocates, including women who had previously experienced perinatal death" (2007, p. 2). Davidson concludes these developments came about in part due to the caregivers response to "medicalization and high technology" by "mediat[ing] its problematic effects with high-touch care" (2008, p. 282), meaning for Davidson "the emotional labour of human response and social interaction that mediates dehumanizing consequences of medical technology" (p. 279). Certain healthcare professionals were increasingly cognizant not only that parents were grieving reproductive losses but that a lack of hospital and social support was an important factor in the parents' emotional pain and/or psychological recovery. Many of these same healthcare professionals, often guided by self-led parent support groups (Layne, 2003), then took it upon themselves to initiate changes in their own labour practices, and these individual changes were eventually institutionalized.

In referencing some of the key texts and programs written for care providers in the 1980s (G.W. Davidson, 1979; 1984; Lamb, 1989; Worden 1982), we find the following components in the new standard of care that was emerging: The validation of grief experienced by the parents; allowing parents to see and hold the baby rather than separating them immediately at birth or after emergency care; facilitating the parents' own arrangement of funeral or memorial services, including decision-making in what would happen to the remains; connecting parents to supportive resources such as on-site social workers and ongoing counselling after their hospital stay; and providing parents with the same kinds of mementos that other parents in the hospital receive when they go home with their newborn, such as the hospital bracelet, a lock of hair, clothing, blankets, birth and death certificates, and so on. Between 1984 and 1989 Judith Lasker and Lori Toedter performed a longitudinal study of almost 200 women and men over two years who had experienced miscarriage, ectopic pregnancy, stillbirth, or newborn death. The authors set out to evaluate what were then new perinatal bereavement support initiatives in the American hospitals at which their participants had experienced their loss. The study found that "[a]lthough few interventions are ranked by the majority as essential, the parents who did experience interventions such as having a photograph and keepsakes of the baby, a memorial service, contact by a social worker or support group, and materials on loss were significantly more satisfied than those who did not" (1994, p. 59); the findings suggest this was particularly true for "parents who experienced a second trimester fetal death" (p. 59).

It is in the development of hospital best practices that EOL photography as a mode

of memory-making and creative representation garners attention in clinical discourse. Again, we can turn to the Resolve Through Sharing training program for examples. As mentioned above, Resolve was one of the first and most central training programs for care providers, established in 1981 by two nurses at the Gundersen Lutheran Medical Center in Wisconsin. The Resolve framework identifies memory creation as "a key strategy for helping bereaved parents," suggesting (amongst other interventions) that "a lasting memory of what the baby looked like can be created by taking photos. This is a one-time chance to create the visual memory that needs to last a lifetime for the parents" (Gensch & Midland, 2000, pp. 288-289). According to the *Family-Centered Maternity and Newborn Care: National Guidelines* document developed in 2000, some institutions developed a Bill of Rights for Parents and Infants.[5] Citing from the Women's College Hospital's (Toronto) *Rights of parents at the hospital: At the time of the baby's death* (1984), parental rights include: "To receive mementos of their baby (e.g. Footprints, picture, certificate of life)." After sending out a questionnaire regarding bereavement photography, a 1988 newsletter by the parental support group SHARE reported that 95% of the 438 parents who completed the questionnaire felt it was important to have pictures of the baby (Laux, 1988). Over the second half of the twentieth century, volumes of research on perinatal bereavement moved innovation into standard practice. Part of nursing and social work labour in the hospitals around the death of a baby came to include memento creation, such as plaster casts of baby's hand

[5] The *Family-Centered Maternity and Newborn Care: National Guidelines* was developed "through a collaborative process involving 70 professionals and consumers across Canada, and facilitated by Health Canada and the Canadian Institute for Child Health" (Source: http://www.phac-aspc.gc.ca/hp-ps/dca-dea/publications/fcm-smp/)

and feet, taking pictures of the baby (and the family when possible), and facilitating other creative activities for parents and siblings, such as journaling, drawing, crafts, and putting together memento boxes (Jung et al., 2003; Ives-Baine et al., 2013). In systematically reviewing more than 1,100 articles from 1966 to 2006 regarding studies of parent experience with hospital care after perinatal death in U.S. hospitals, Gold, Dalton, & Schwenk (2007) identify "obtaining photographs and memorabilia of the deceased infant" as one of five "aspects of recommended care" that are sometimes offered but in need of improvement.

As we see above, much of the literature on EOL photography has been written by clinicians for clinicians, most often in the form of psychological research supporting the development of bereavement protocols in medical institutions. Coming from outside this medical framework, my research's sociocultural focus reveals dimensions unmapped by the existing literature. For one, my focusing research question does not pertain to the parents' "satisfaction" with the hospital's bereavement services and protocol. On one hand I find the language of "satisfaction" phenomenologically rich in that it captures a sense of satiation or being filled. On the other hand, this rubric positions the parents as consumers taking in a service more so than engaging with an embodied practice within an immersive space-time. The language of "satisfaction" also neglects to specify what need or desire was satiated in the first place, to what degree and in what form.

I am less interested in the photography as intervention, which we find in the majority of available literature on EOL photography in healthcare (see Sexton 1991;

Leon, 1992; Calhoun, 1994; Lasker & Toedter, 1994; Sanchez, 2001). My interest in this photography is much broader; participants were invited to reflect on any aspect of the photography they wanted to, but it was made clear in explaining the study at the beginning of each interview that I was not interviewing them on behalf of the hospital. I did not set out to validate the practice or objectively measure the success of clinical bereavement management, but to provide insight into how parents experience this photography. The research focus and interview questions did not impose the language of intervention or service satisfaction, but invited participants to navigate their grief, mourning and healing through their own language and meaning-making. Confidentiality was also provided to participants so they could speak freely about their experiences in the hospital in a way that might not be possible in research conducted by the care providers directly. In practical terms, this meant that while the Coordinator facilitated my contact with the parents, she did not know who responded to the invitation to participate, she did not sit in on the interviews, and she did not access identifying information. Parents did have the option of self-disclosing to the Coordinator, however, which many felt comfortable doing based on the relationship they had established during their time in the NICU.

The study was also designed to consider not only the parents' experience of the photography in the hospital setting, but in their life beyond the NICU as well. While the study is not longitudinal, the participants were a minimum of one year away from their loss based on inclusion criteria and were able to reflect on their experiences over that

period.[6] We see a similar focus on how parents live with the photographs beyond the initial impact of loss in a study published by Gordon Riches and Pamela Dawson (1998). Riches and Dawson's fieldwork included in-depth and open-ended interviews with 36 bereaved parents, various bereavement groups and conferences between 1994 and 1996 (Riches & Dawson, 1998, p. 128). In the 1998 *Death Studies* article summarizing the results, Riches and Dawson identify "four distinct ways that photographs and other artifacts appear to help bereaved parents organize and use the memory of their child," including: "providing concrete evidence that the child actually existed"; "the opportunity to explore remembered (or newly discovered) places and points in time that children were associated with prior to their deaths"; to "enable parents to relive significant events, turning points and cherished shared experiences from which a memory of the life as a whole can be constructed"; and to "provide a resource helping parents construct a public, post-bereavement self" (pp. 127-128). Some of these findings resonate with my own and are interesting to note, but overall the studies are not comparable based on the participant sample. In the Riches and Dawson study, the sample of ages at which the children had died ranged from prenatal to 32 years of age (p. 126), meaning many of the photographs and mementos the parents discuss are from different places and times across their child's life, even into adulthood. This makes for a qualitatively different study than one focusing on photos taken in the hospital that are then brought into the parents' lived environments beyond that initial setting. The scope of my research question and study sample acknowledges a

[6] In the end, all participants were between two and four years away from their loss.

meaningful specificity of both the photographs *and* the act of photography in neonatal palliation and bereavement.

A relevant point Riches and Dawson bring to light, however, is an important genealogical factor in the late twentieth century emergence of bereavement photography. The authors frame their interest in photographs and memorabilia through the proposal "that grief is, at least in part, a process through which bereaved parents review and reorder their child's significant life events, in conversation with others, so as to produce a memory with which you can live" (p. 127). Their framework draws on a number of key bereavement scholars who were reworking the dominant model of grief around the time of Riches and Dawson's research. The dominant model of grief—with a lineage to Freud's melancholic subject laid out in his influential *Mourning and Melancholia* (1917)—took healthy grief to resolve with the eventual detachment from the deceased, versus pathological grief that maintained an ongoing attachment preventing the bereaved from forming new attachments. The new understanding emerging in the last twentieth century, however, came to normalize the attachment or "continuing bonds" (Klass, Silverman & Nickman, 1996) that individuals maintain with the dead. Tony Walter (1996) contributes the idea that part of this ongoing attachment is the construction of a "durable biography" for the deceased, constructed and maintained through the survivors' conversations, memories and memorial objects. It is significant that EOL photography appeared around this late twentieth century shift in grief theory, as the correspondence intimates how clinicians would come to accept photographs of the deceased as a healthy part of grief management. However, as my findings show,

what is also important to consider is the way in which photography as a practice fosters not only "continuing bonds" after the fact of death, but what I term "living relationships" in the NICU while the baby is alive. By "living relationships" I mean the embodied proximity and time spent building relations with other individuals that come to constitute one's life-story, discussed further in Chapter 4.

It is pertinent to point out that aside from the research into the clinical management of perinatal bereavement, my literature review revealed a lack of discussion on EOL photography in texts that were written for or by physicians, surgeons, and/or obstetricians. Outside of the psychological and psychiatric research into perinatal bereavement generally, the primary clinician group publishing on EOL photography as a healthcare practice are nurses.[7] Again, this ties back to Davidson's research concluding nurses were at the forefront of developing perinatal bereavement protocol, based on their lived experiences with families bereaved by these losses (2007; 2008). Professional organization and knowledge specialization are partially responsible for the way in which nurses take the front line of bereavement support in neonatal care. Like many hospital units, the NICU distinguishes between active treatment versus palliative care, of which EOL care is a facet. According to Health Canada: "Palliative care addresses different aspects of end-of-life care by: managing pain and other symptoms; providing social, psychological, cultural, emotional, spiritual and practical support; supporting caregivers; and providing support for bereavement."[8] Bereavement protocol such as EOL photography, then, often falls under the auspices of EOL, carried out by an

[7] For examples of this literature see Alexander, 2001; Workman, 2001; McCartney, 2007

[8] Source: http://www.hc-sc.gc.ca/hcs-sss/palliat/index-eng.php

even more specialized group of nursing staff assigned to EOL committees.

More than a matter of administrative structure, however, we must make sense of the sparse knowledge-production around EOL photography as a practice and an experience by considering the broader epistemological conditions of its emergence. For one, we can more pointedly define the contemporary Western hospital setting as a biomedicalized space. This categorization signals a move beyond the mid-twentieth century processes of medicalization to the transformation of "old and new social arrangements that implement biomedical, computer and information sciences and technologies to intervene in health, illness, healing, the organization of medical care, and how we think about and live 'life itself'" (Clarke et al., 2010, p. 1). If, as Adele Clarke and co-authors suggest, "[m]edicalization practices typically emphasize exercising *control over* medical phenomena—diseases, illnesses, injuries, bodily malfunctions," we can take biomedicalization practices to "emphasize *transformations of* such medical phenomena and of bodies, largely through sooner-rather-than-later technoscientific interventions not only for treatment but also increasingly for enhancement" (2010, p. 2, emphasis in the original). Although Clarke et al. locate biomedicalization as a transformation of the American medical arena around 1985, we can identify the technologies and techniques throughout other regional and global health systems within technological intervention, a focus on enhancement and optimization, discourses of risk and surveillance, and "the imbrications of capital with the biological sciences and technologies" (p. 7). In other words, biomedicalization is not the culture of any one given hospital setting, but rather a pervasive way of knowing that gives logic to

a network of expertise, practices, technologies, and structures. As an apparatus, biomedicalization produces, disciplines and securitizes a biomedical subject whose life and death are to be controlled and administered through technoscientific means.

An epistemic foundation of biomedicalization is a strict reliance on objectivity and removal of emotional, subjective, spiritual, or contextual ways of knowing from medical practice: individuals are discursively produced as quantifiable "molecular" selves (Rose, 2007), practitioners as rational decision-makers, and science itself is the "god-trick," the "view from above, from nowhere, from simplicity" (Haraway, 1991, p. 195). The practical model for this epistemology is Evidence-Based Medicine (EBM), the "ideology and technique" of which has been accredited to British physician Archie Cochrane's *Effectiveness and Efficiency Random Reflections on Health Services* (1972) (Hjorland, 2011, p. 1301). The Evidence-Based Practices (EBP) developing out of EBM include a number of criteria, such as: that "decisions in practice should be based on the best available "evidence"; that "Evidence" should be understood as research-based knowledge (published or unpublished)"; that "the documentation, collection, and interpretation of evidence should be published as a "systematic review"; and that "[e]xplicit norms should be made for investigation that are most relevant, and a hierarchy of the value of different kinds of research methods as evidence should be made" (p. 1302). Topping the list of most valued research methods in EBP include "meta-analysis of randomized controlled trials (RCTs)" (p. 1302). RCT's aim to remove the variable of context from findings mirrors the broader epistemological value modern science has long placed on objectivity; it came to be that

> [o]nly the biomedical aspects of a person that could be measured and quantified were considered scientific enough and consequently all immeasurable aspects, such as those that belong to one's mind, thoughts, feeling, wishes, intentions and other existential phenomena, were left outside of the scientific domain. (Dahlberg, 2011, p.19)

For this reason, the 'evidence' provided by qualitative inquiries into lived experience can come under question by medical institutions.

These epistemological issues are not simply philosophical, but play out in very practical ways. For example, I refer to a book titled *Maternal-Fetal Evidence Based Guidelines* (2007), published in a Maternal-Fetal Medicine series by Informa Healthcare, in the United Kingdom. The text sets out to

> summarize the best evidence available in the obstetrics and maternal-fetal medicine literature, and make the results of randomized trials and meta-analyses easily accessible to guide clinical care. The intent is to bridge the gap between knowledge (the evidence) and its easy application. (Berghella, 2007, p. 1)

In a chapter on "Fetal Death" it states: "Grief counselling should be initiated prior to discharge from hospital. No information is available from randomized trials to indicate whether there is or is not a benefit from providing specific psychological support or counselling after perinatal death" (p. 321). This statement, while perhaps based on accurate meta-analyses of literature, dismisses the informal knowledge that care-givers have acquired about the value of EOL photography through their first-hand experience with families. Anecdotal evidence, even when copious, does not meet the EBM

mandate to systematize, isolate, control, make certain, and remove subjectivity.

I agree with Kim Walker (2009) that the EBP mandate appears "misguided," as it

> is the unrelieved messiness of clinical practice life "in the flux" that renders each and every decision so fraught with potential peril; this is simply a fact of life and will never be erased, no matter how much knowledge we can produce or ever cleverer interventions we can design. (p. 25)

Haraway and other feminist epistemologists have called for a science embracing rather than denying this messiness. Haraway (1991) argues

> for politics and epistemologies of location, positioning, and situating, where partiality and not universality is the condition of being heard to make rational knowledge claims. These are the claims on people's lives; the view from a body, always a complex, contradictory, structuring and structured body" (p. 195).

I have designed my own research on the tenets of situated knowledges, holding that a phenomenological analysis of participants' lived experiences stands against "that dream science/technology of perfect language, perfect communication, final order" to align with "the sciences and politics of interpretation, translation, stuttering, and the partly understood" (p. 195).

2.2 Neonatal Bereavement as Communication and Cultural Practice

In reviewing a cross-section of communication studies, media studies and cultural studies literature, I discovered almost nothing written about EOL photography to date.

One of the more extensive handlings of the topic is found in Margaret Godel's 2007 *Visual Studies* article exploring images of stillborn babies and their function in creating the baby's social identity. This piece was not based on parent interviews, however, and focused exclusively on stillborn abies, so was not able to offer insight into photography that takes place across a newborn's life *and* death. Godel's work aside, my review found two books that discuss EOL photography in some detail: Jay Ruby's *Secure the Shadow: Death and Photography in America* (1995) and Audrey Linkman's *Photography and Death* (2011).

Secure the Shadow aligns with the majority of Ruby's work as an anthropologist of visual communication, explaining EOL photography as a residual practice from Victorian memento mori customs. Linkman is an independent photo historian who wrote *Photography and Death* and put together various exhibitions on post-mortem photography after the death of her father in the early 1990s. Similar in scope, Ruby's work "is an exploration of the photographic representations of death in the United States from 1840 to the present" (Ruby 1995, p. 1), while Linkman "primarily focuses on Western traditions of mortuary photography from 1839 to the present" (Linkman 2011, p. 8). Both frame the "sudden revival" (Linkman, p. 80) of EOL photography as a vestige of western mourning traditions that unexpectedly re-emerge 100 years after their Victorian prime, even if practitioners are not aware of the connection to past customs (Ruby, p. 180). Overall, both Ruby and Linkman's contribution on EOL photography remains more descriptive than analytic, aligning with other photography studies work on Victorian memento mori (Meinwald, 1990; Burns, 1991; Burns & Burns, 2002;

Hirsch, 2009).

The discussion of EOL photography in *Secure the Shadow* and *Photography and Death*, which is based more on archival work than on original empirical research, mirrors the medical literature mentioned above in that it is primarily written from the perspective of clinical bereavement practitioners. Linkman suggests "the production of post-mortem portraits of stillborn and neonatal infants was actively encouraged in the belief that they would assist parents' recovery from the loss of their child and circumvent any pathological consequences" (p. 80), but does not mention the parents' experiences with or perspectives on the practice. Ruby notes a study published in 1986 by The National Stillbirth Research Project of the University of Nebraska that interviewed 22 families and surveyed 350 mothers of stillborn children; the survey results reported "many parents thought that seeing the baby in a photograph was an important part of their recovery from the loss" (Ruby, p. 181). Outside of this mention and four paragraphs from the interviews, Ruby reiterates literature from healthcare professionals who had implemented the practice in their institutions. Importantly, Linkman and Ruby look exclusively at post-mortem photos without distinguishing between babies who are born still versus neonatal deaths, nor providing detail on the specificities of photographing a stillborn baby just after birth, versus photographing the death and life of a newborn anywhere from a few hours to a few months in a NICU. This oversight is significant, as I found in my interviews some families do not consider much of the photography that takes place in intensive care "bereavement" photography at all; I noted that where parents picked up on the language of "bereavement

photography" most was in instances where the majority of their photos were taken around the newborn's death specifically, as opposed to throughout the baby's life and death.

A second consideration is how Ruby and Linkman overlook the camera technology itself, giving no analysis of the relation between technologies and practices. While *Secure the Shadow* was published prior to the widespread development of digital technology, *Photography and Death* was written over fifteen years later; still, Linkman mentions only the move from Polaroid to archival film for durable image preservation. One of the significant contributions my research makes is that it purposefully accounts for the fact that the photographic technology available for care-providers at the advent of neonatal bereavement support in the 1980s is strikingly different than the cameras, printers and editing software created in the mid to late 1990s with digital technology. Even then, early incarnations of digital photography appear distant from more contemporary technologies now available. The accessibility and mobility of high quality cameras has increased with the production of such things as cell phone cameras in the early 2000s and tablet computers in the last few years. Because all participants in my sample had experienced their newborn death in the same NICU within five years of each other, the photographs were taken and shared with relatively similar technologies. I account for my approach to photographic technologies and the move from film to digital in more detail in this chapter's final section.

With the development of social media software that gained popularity in the early 2000s, it is not only camera technology that needs addressing. Linkman touches on

Internet technology in the twenty-first century, saying the appearance of portraits of stillborn infants and perinatal deaths on the web "would seem to be a logical extension of an official attitude that encouraged the memorialization of such deaths" (p. 83). While Linkman briefly talks about such sites as web memorials and YouTube, she does not distinguish between open-access or community sites and those, such as Facebook, that connect the parents to their immediate social network (distinct from a bereavement community in web memorials) and allow parents to control or open privacy in more direct ways. My interview questions addressed online social networking specifically, in recognition of the unique photo sharing capabilities these applications offer and in interest of how parents negotiate the public/private dimensions of one's own online social network as a place to potentially post their photos taken in the NICU.

As a critical cultural communication project, this dissertation is interested in "not ideas but in things" as James Carey often said about his approach, quoting poet William Carlos William (Stryker, Munson & Warren, 1997, p. 9). In other words, I do not analyze EOL photography in terms of symbolic content, as found in other research such as Rosemary Mander and Rosalind Marshall's 2002 *Midwifery* article examining current and historical representations of "the dead baby" through a review of literature and paintings (2002, p. 231). I am not expelling culture, but proposing technology is "intrinsically cultural" (Carey, 1989, p. 317). Following the cultural approach to communication that Carey articulated in *Communication as Culture: Essays on Media and Society* (1989), I consider communication, and photography specifically, not just as message transmission, but meaning, form, history, technology, community, and

struggle. The premise that communication as culture is not only symbolic representation but also material embodiment in space-time informs the phenomenological questions I ask about photography in and through social spaces, temporalities, mobilities, and discursive fields as matters of corporeality. Jeremy Packer and Stephen Wiley (2012) have articulated "a turn to the body" (p. 4) as one amongst other strategies for thinking about the materiality of communication and culture. Packer and Wiley extrapolate from this observation:

> Our networked media-bodies are implicated in biopolitical struggles that cross human, animal, and technological thresholds—a state of affairs that forces us to recognize the body is more diffuse, less fixed, and more pervious than once was thought. Media are central to such extensions, distributions, interpenetrations, and malleabilities. (p. 4)

In dialogue with such materialist strategies, my phenomenological framework explores how lived experiences are produced by but also exceed the system of discourses, procedures, spaces, temporalities, techniques, and technologies that constitute what Giorgio Agamben has identified as an "apparatus," expansively defined as:

> literally anything that has in some way the capacity to capture, orient, determine, intercept, model, control, or secure the gestures, behaviors, opinions, or discourses of living being. Not only therefore, prisons, madhouses, the panopticon, schools, confession, factories, disciplines, juridical measures, and so forth (whose connection with power is in a certain sense evident), but also the pen, writing, literature, philosophy, agriculture, cigarettes, navigation,

computers, cellular telephones and—why not—language itself. (2009, p. 14)

Karen Barad (2007) also provides a helpful definition of "apparatus," saying they "are specific material reconfigurations of the world that do not merely emerge in time but iteratively reconfigure space-time-matter as part of the ongoing dynamism of becoming" (p. 142). Following these usages, I do not see the biomedical apparatus always-already containing and determining all experience around death-in-birth; like all apparatuses, it is leaky, experiences are fleshy, and between the two Agamben's "living being" ends up a slippery concept to hold on to.

2.3 EOL Photography as Embodied Practice: Theoretical and Methodological Interventions

i) Developing a Critical Phenomenological Framework

I crafted this research project around two interrelated goals: One objective was to conduct empirical research that validates participant authority on their own birthing, their own grieving, their own mourning, and their own healing; The other aim was to critically analyze the cultural politics of EOL photography as a media practice. In designing a study around these goals, I turned to existential phenomenology as a means of conceptualizing the participants' lived experiences and to a Foucauldian genealogy and theory of power/knowledge as a means of analyzing how parents are produced as "bereaved subjects," how critically ill newborns are constructed as "dying subjects" and how they were both produced as "photographic subjects." If we do not accept that EOL photography is a timeless transcendental practice, than in turn we accept that it is of a certain time, certain space, certain knowledge. I am not aware of any existing empirical

work in communication studies or cultural studies that combines existential phenomenology and Foucauldian analysis within one methodology and believe my research contributes an original example of this approach, upon which I intend to build future research. I was able, however, to find examples of scholars intersecting the philosophy and praxis of phenomenology with critical frameworks to explore political and ethical potentials (see Connolly, 2010; Coole, 2010; Murray, 2012; Murray & Holmes, 2013a; 2013b). I turn to the bases of my own inquiry into such matters now.

While phenomenological inquiry is popular in health discipline studies interested in patient experience, it was difficult to find a methodological model for a sociocultural project that did not identify participants as "patients" or, further, was sensitive to questions of subjectivity, mediation, meaning, and embodiment on theoretical and methodological levels. Part of the issue is that the phenomenological research paradigm was developed by phenomenological psychologists (Groenewald, 2004), complete with the cognitive trappings one would expect from a framework crafted in a clinical field. Another issue is that many existing health studies do not specify the phenomenological philosophy upon which they base their inquiry, making for unclear and even inconsistent methodological choices upon which to model other work (Lopez & Willis, 2004; Norlyk & Harder, 2010). For example, two of the dominant approaches to phenomenological study are descriptive (based on a Husserlian approach that puts forward a primacy of *description*) and hermeneutic (based on a Heideggerean approach that puts forward a primacy of *interpretation*) (Giorgio & Giorgio, 2007; Wojnar & Swanson, 2007). However, based on their review of nursing

and clinical studies, Lopez and Willis (2004) conclude:

> A problem with many qualitative studies is the absence of linkage between the method used and a clear statement of the philosophical underpinnings that should guide the method (Stubblefield & Murray, 2002). Implementing a method without an examination of its philosophical basis can result in research that is ambiguous in its purpose, structure, and findings. (p. 726)

To make my own linkage between method and philosophy clear, I put together a mode of data collection and analysis based on the model for Interpretive Phenomenological Analysis (IPA) developed by Smith, Flowers & Larkin (2009). This model assumes subjects are "sense-making creatures, and therefore the accounts which participants provide will reflect their attempts to make sense of their experience" and that "access to experience is always dependent on what participants tell us about that experience, and that the researcher then needs to interpret that account from the participant in order to understand the experience" (Smith, Flowers & Larkin 2009, p. 3).

The version of IPA Smith, Flowers & Larkin put forward, however, is based on the earlier work of Smith, Harré, and Van Langenhove to "rethink psychology" (1995), and is still missing a desirable philosophical base for my research. While I identify my analysis as hermeneutic—in fact a double hermeneutic in which participants interpret their experiences and I interpret that interpretation—I did not want my methodology to take these interpretations as a cognitive or textual practice, 'reading' the language used to describe or overlay a more pure experience. It was crucial to neither reduce the participants' described experiences nor the EOL images to text. In this way, my mode

of interpretive analysis is what I term embodied-hermeneutic, based on Merleau-Ponty's philosophy of corporeality which refuses to dichotomize meaning and experience, but instead brings them together in the "sense experience" which he sees "invest[ing] the quality of [the world] with vital value" and meaning, always in reference to the body conceived as the "incarnate subject" or "body-subject" (Merleau-Ponty, 1962, p. 61).

The situated body-subject contradicts the assumption of an abstracted or dualist object/subject, which is particularly relevant in a project exploring experiences within a clinical setting. The reliance on a biomedical paradigm can in some instances hollow out, dislocate or generalize body-subjects in the name of the universal patient-consumer. In accordance with Stephen Priest's summation of the ethical importance of the body-subject in a clinical context, "[t]he progress of objective science should never be permitted to obfuscate our lived existence as subjective, conscious, choosing and feeling human beings" (2000, p. 174). Based on their own qualitative fieldwork, Murray and Holmes (2013b) further make a compelling argument for "using Merleau-Ponty's phenomenology of the body and place, as well as his related treatment of language and embodied speech" to the practice of IPA. The authors call for "ethical analysis" to begin "through an investigation into the ways that subjectivity is constituted":

> We turn to Merleau-Ponty's understanding of *parole parlante* (speaking speech) in order to reorient ethics as a matter of bodies that speak, where speech represents the struggle to make sense of experience and to communicate that experience to oneself self-reflexively as well as to others. It is in this context, we

> suggest, that the subject can appear as the bearer of an ethical claim, whether that claim is situated in the actions of a body or as vocalization. Implicit here is a critique of cognitivist psychological approaches to phenomenology, biomedicine, and (bio)ethics, which often figure bodies as problematically lifeless and abstract. (Murray & Holmes, 2013b, para. 1)

Picking up on the significance of "place" that Murray and Holmes highlight, my findings reveal that the NICU is not a neutral background to participant experiences, but constitutive of both these experiences and the EOL photography as an embodied practice involving care-providers, families and newborns. While I recognize there is a rich dialogue on the terminology and conceptualization of 'space,' 'place' and 'time' in critical geography, communication studies and elsewhere, the scope of this dissertation does not permit me to provide a complete or systemic review of that literature. However, to clarify what I term "space-time" throughout the following chapter, it can be said that I borrow from Merleau-Ponty's (1962) definition of "space", proposing it "is not a setting (real or logical) in which things are arranged, but the means whereby the position of things becomes possible" (p. 284). I add the experiential and the social dimensions of temporality to this definition, acknowledging that "[t]ime is produced at the intersection of a range of social differences" and "the temporal, something quite different than tempo, is a form of social power, a relation of difference, and a material struggle" (Sharma, 2011, p. 440). By this account, space-time is not an empty container but a structure of lived experience that is meaning for the body-subject; space and time are lived space and time.

Because body-subjects are in the world together, I draw from the work of feminist geographer Doreen Massey (2005) who puts forward an approach to space as produced by interrelations and interactions, as a sphere of heterogeneity, and as "always under construction" (p. 9). In other words, the NICU is always "being made" by the material practices and "relations-between" (p. 9) that produce it as a sociocultural site of reproductive health and reproductive death. Lived space and time do not contain the body-subject, but rather position the body-subject in relation to others; this position is not a determination but a negotiation. In other work, Massey (1994) suggests we think of "social space in terms of the articulation of social relations which necessarily have a social form in their interaction with one another" (p. 120). Following this suggestion, social space—or in Massey's terms "place"—can be thought of

> as particular moments in such intersecting social relations, nets of which have over time been constructed, laid down, interacted with one another, decayed and renewed. Some of these relations will be, as it were, contained within the place; others will stretch beyond it, tying any articular locality into wider relations and processes in which other places are implicated too. (p. 120)

Here we see the idea that space is both structured and leaky, both singular and multiple, both constructed and emergent, a location but also always in-between.

I bring together these conceptualizations of space-time with Foucault's assertion in *The Archaeology of Knowledge* (1969) that "knowledge is also the space in which the subject may take up a position and speak of the objects with which he deals in his discourse" (p. 201). This statement comes in Foucault's earlier archaeological work in

which he distinguishes between knowledge as 'savoir' (the condition for a specific body of knowledge to emerge) versus 'connaissance' (the corpus itself). Here we see scientific disciplines of knowledge captured in the term 'savoir,' while 'connaissance' leaves room for a more embodied sense of the conditions that make something sayable, seeable and—I would add in a phenomenological note—*sensible*.[9] Pausing on the language, we might hear connaissance as co-naissance, as in co-birth, the subject and space re-producing each other in a set of meaning-full actions. We can take the 'space' in Foucault's assertion to be "the means whereby the position of things becomes possible," to return to Merleau-Ponty's words; then we have space as a horizon for the body-schema and perception of the things in one's life-world, which can also be articulated as the place of intersecting social relations that produce the subject. In accordance with Merleau-Ponty, "Existence… cannot be anything—spatial, sexual, temporal—without being so in its entirety… with the result that an analysis of any one of them that is at all searching really touches upon subjectivity itself" (1962, p. 477).

In combining Merleau-Ponty and Foucault, my methodology addresses the concern Joan Scott (1991) and others have raised in terms of 'experience' being understood to assume an essentialized transcendent subject whose own identity guarantees the Truth of its experiences, thus reinforcing the very power structures from which the identity is formed. Scott echoes Foucault's argument that "[o]ne has to

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[9] In her work on intercultural film, Laura Marks also makes the argument for recognizing the realm of the sensible in addition to the seeable and sayable in terms of a Foucauldian archaeology of images. Mark's argument is found here: Marks, L.U. (2000). "The Memory of Images." *The Skin of the Film: Intercultural Cinema, Embodiment, and the Senses*. Durham: Duke University Press, pp. 24-77.

dispense with the constituent subject, to get rid of the subject itself, that's to say, to arrive at an analysis which can account for the constitution of the subject within a historical framework" (Foucault, 1980, p. 117). In this assertion Foucault makes the case for a genealogical methodology, which is to analyze the "pure experience of order and of its modes" (1994a, p. xxi) and "create a history of the different modes by which, in our culture, human beings are made subjects" (1994b, p. 208). Foucault deals directly with this concept in his essay "Nietzsche, Genealogy, History" where he defines genealogy against history by way of detailing Nietzsche's "challenge [to] the pursuit of the origin" (Foucault, 1994c, p. 371).

What Scott and Foucault bring to light is a need to account for power relations if one is to take experience as knowledge. I agree entirely that this is a substantial concern, conceding a theory of power must be central to having phenomenological methodology move beyond mere description; this is what my methodology contributes to existing literature in communication and cultural studies. What I propose in accordance is that there is no necessary aporia between the subject of lived experience and the subject of power's construction if we accept there is no necessary dichotomy between language and experience. Here discourse becomes not a system of representation, but a system of events within which the embodied subject is constituted, thus acknowledging an immanent connection between subject, experience and discourse. This evokes the work of feminist theorist and scientist Karen Barad (2003), who challenges what she identifies as the many theoretical turns (i.e. the linguistic, the semiotic the interpretive, the cultural) through which "every "thing"—even

materiality—is turned into a matter of language or some other form of cultural representation" (p. 802). Barad responds with a "*performative* understanding of discursive practices" that "challenges the representationalist belief in the power of words to represent preexisting things… performative is precisely a contestation of the excessive power granted to language to determine what is real" (p. 802, emphasis in the original). [10] Barad's call to the performative invites us to rethink discourse, power, bodies, and subjectivity through embodied experience without underestimating how experience is always-already meshed with power relations, produced by power but also produced by itself as a power-full agent.

I am not suggesting that one's experience provides access to a transcendental truth, but rather that our lived experience, even if relayed through language, is central to our understanding the "truth regimes" (Foucault) within which we are formed as subjects. The key is to understand both experience and power as relational rather than objective. Power understood as a "relationship of violence" can only "act[] upon a body or upon things; it forces, it bends, it breaks, it destroys, or it closes off all possibilities" (Foucault, 1994b, p. 340). In this formulation there is no embodiment, but simply bodies that can only be the "opposite pole" of violence, which is "passivity." In contrast,

> [a] power relationship… can only be articulated on the basis of two elements that are indispensable if it is really to be a power relationship: that "the other" (the one over whom power is exercised) is recognized and maintained to the

[10] Barad reworks Judith Butler's theory of performativity in her book *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning* (2007), Durham: Duke University Press.

> very end as a subject who acts; and that, faced with a relationship of power, a whole field of responses, reactions, results, and possible inventions may open up. (p. 340)

In a power relationship, Merleau-Ponty's account of the embodied subject can be thought of as the material and affective site for these responses, reactions, results and possible inventions.

Experience is being, and consciousness is being towards something, therefore "meanings are not *given to* experience, but *received from* it" (Merleau-Ponty, 1962, p. xi). From here we can argue discursive meaning is received from our experience. Our response to the world can be articulated as perception, which is not split in the mind nor body, nor in sensed or sensing, but in the "flesh":

> The flesh is not matter, is not mind, is not substance. To designate it, we should need the old term "element," in the sense it was used to speak of water, air, earth, and fire, that is, in the sense of a *general thing*, midway between the spatio-temporal individual and the idea, a sort of incarnate principle that brings a style of being wherever there is a fragment of being. The flesh is in this sense an "element" of Being. Not a fact or a sum of facts, and yet adherent to *location* and to the *now*. (Merleau-Ponty, 1969, p. 140, emphasis in the original)

Merleau-Ponty is careful to argue against the definition of perception as "a *function* of exterior *variables,*" suggesting "the stimuli of perception are not the causes of the perceived world… they are rather its developers or its releasers, we do not mean that one could perceive without a body; on the contrary we mean that it is necessary to

re-examine the definition of the body as pure object in order to understand how it can be our living bond with nature" (p. 26-27). This language of "developer" or "releaser" ("révélateur") nicely conjures the darkroom's chemical baths bringing forth—but not creating or causing—the image that was latent on the photographic paper. The perceptual body is not an object coming at the world, causing the world, nor guaranteeing absolute knowledge of any thing in question. Perception is also not 'thinking' in the sense that to perceive something is not to have an idea of it (though these acts come later). Perception is rather "inhabiting" the world (Merleau-Ponty, 1964, p.140)—it *is* the body as experience. The idea that the fleshy body's "being-in-the-world" (a Heideggerean term borrowed by Merleau-Ponty) is a constantly transformative process resonates both with Rosi Braidotti's nomadic subject, which I explain further in the proceeding chapter, as well as the relational subject Foucault describes. The subject is within and makes up "the field of possibilities in which the behaviour of active subjects is able to inscribe itself" (Foucault, 1994b, p. 341). Power "operates" within this field as "a set of actions on possible actions" (p. 341).

There is a becoming-subject element to the embodied subject I put forth here that is critical to understanding how we experience power relations, and therefore also how we are able to resist or transform them from within. To validate a person's interpretation of his/her own lived experience is to validate their speech in the ethical terms laid out by Murray and Holmes above. It also works towards what Foucault calls "a new economy of power relations," which "consists in taking the forms of resistance against different forms of power as a starting point… it consists in using this resistance

as a chemical catalyst so as to bring to light power relations, locate their position, find out their point of application and the methods used" (Foucault, 1994b, p. 329). One's actions can be a form of resistance against the "conduct of conduct," and here we can understand Foucault's "chemical catalyst" in the same light we understand Merleau-Ponty's "révalateur"—in both, the body reveals the power relations within which it exists.

Throughout this dissertation I question how technologies, or perhaps more accurately *techniques*—of health, of illness, of dying, of reproduction, of memory, of (dis)connection, of capture, of light, of archive—organize bodies as subjects *and* how individuals take up these material formations of space-time as their own lived experience. How, in other words, do newborns and their families become photographic subjects within a clinical setting? How do the families experience the photographic in this context? My methodology recognizes that both experience and power/knowledge are central to this examination of EOL photography. The lived body or body-subject is not timeless or *outside* the language, meaning, spaces, temporalities, and things that constitute "knowledges, discourses, domains of objects, etc." (Foucault, 1990, p. 117), but this interior position is the heart of its analytic significance in my work. In this formulation I also acknowledge the newborns whose photos were taken, refusing to render them invisible in this work. This is one of the reasons I have included their images throughout this document.[11] I acknowledge their complex subjectivity that is spoken, seen and sensible—by their families, by the care-providers and by the

[11] I have only included photos from families who provided written consent to having images reproduced for this research.

biomedical apparatus within which they live and die—even if they are not subjects who can communicate their own experience in forms that allow for phenomenological analysis.

ii) Bringing Photography Back to Life

The methodology I have just outlined is the foundation upon which I build my fieldwork analysis and my approach to photography as a media practice in general. While I align my framework with the phenomenological work found in Roland Barthes' *Camera Lucida* (1984), this dissertation also functions as a challenge to the conclusion about photography Barthes makes in chorus with myriad other theorists over the last many decades of photography theory: The notion that photography is a medium of death, pastness, mourning, melting mortality. I argue the oft-repeated connection made between photography and death comes out of confusion between phenomenology and ontology that needs to be addressed as I situate my work on photography and death-in-birth. I further contend this connection must be unhinged if we are to imagine new possibilities for photography and palliative care.

To start, we can consider André Bazin's seminal essay *The Ontology of the Photographic Image* (1960). In this piece Bazin claims "the photographic image is the object itself, the object freed from the conditions of time and space that govern it… it shares by virtue of the very process of its becoming, the being of the model of which it is the reproduction; it *is* the model" (p. 8, emphasis in the original). Bazin is drawing on Charles Pierce's semiological notion of a sign embedded in its object, just as Susan

Sontag (1977) and Christian Metz (1985) did after him, to distinguish photography not only as "an interpretation of the real" but "also a trace, something directly stencilled off the real, like a footprint or a death mask" (Sontag, 1977, p. 154). As Mikael Pettersson (2011) has rightfully pointed out, however, "one cannot reasonably take this as an ontological claim. That is what Bazin intends cannot reasonably be the idea that image and object are one and the same, for they are not" (p. 186). Because the material referent of a photograph has not been physically transported to the time and place within which one is viewing the photograph, we have to question the nature of the "trace" that these theorists are saying exists within the photograph as part of its essence. In technical terms, they are writing in a time of analogue photography, referring to the "trace" as the light bouncing off the subject, through the lens, hitting the film negative[12]. However, both Bazin and Sontag then ignore the series of chemical baths needed to activate the exposed particles on the film negative, readying it to be printed through yet another process of burning or dodging the surface of light-sensitive paper. While in Bazin and Sontag's thinking the photographic trace is light itself, it is in fact the light-activated particles on the film negative, which are reactivated by developing chemicals then projected onto photo paper that is activated once more by light filtering through the exposed/unexposed surface of the negative. Photo-graphy—light-writing—entails a series of different lightness/darkness processes before the image appears. Light

[12] While there was much dialogue in visual studies around the 1990s on whether or not digital technology eliminates the "trace" of film photography and thus challenges the medium's realism, I agree with Sarah Kember's 1996 article in *Textual Practice* titled "The Shadow of the Object" that fears around the loss of the real in digital photography largely reflect a projected panic around the loss of our psychological and social "investment" in the photographic real. Digital photography still relies on light hitting a sensor; its lack of 'realness' depends on a sense that digital encoding stands between a 'real' subject and a 'false' electronic interpretation, presenting a problematic dichotomy similar to language/real, body/culture, etc.

is a massless form of energy, intensity, radiation, frequency, waves, temporality; it cannot be transported and certainly does not travel directly through an image, even if its properties are needed to reveal other chemical properties that are burnt into a printed photograph. Bazin saw photography "embalm[ing] time" (p. 8), as a medium of mummification. However, the proposed ontology of a photograph as mummification or death overlooks a series of quite vitally responsive becomings that eventually create an image. Perhaps snapping a photograph is tantamount to participating in another person or object's "mutability," to paraphrase Sontag (1977, p. 15), but the potential for mutation can also be understood as characteristic of a fleshy, imminent, nomadic subject; the photographic relation is an ethical relation that does not inherently rely on seeing the Other as an object, but seeing others as becoming. Here one could reference the work of new feminist materialist thinkers such as Sarah Kember and Joanna Zylinska (2012) who claim, "Contrary to its more typical association with the passage of time and death, photography can be understood more productively in terms of vitality, as *a process of differentiation and life-making*" (p. 72, emphasis in the original). These co-authors conceptualize photography "*in terms of mediation—whereby mediation stands for the differentiation of, as well as connection between, media and, more broadly, for the acts and processes of producing and temporarily stabilizing the world into media, agents, relations, and networks*"; this conceptualization then leads them to an ontology of photography as one of "*becoming*" (p. 77, emphasis in the original). As they argue: "It is, paradoxically, precisely in its efforts to arrest duration, to capture or still the flow of life—beyond singular photographs' success or failure at

representing *this* or *that* referent—that photography's vital forces are activated" (p. 72). More specifically, and with more interest in process than in ontology, in Chapter 7 I reference Kember and Zylinska's idea that photography is in "an active practice of cutting through the flow of mediation, where the cut operates on a number of levels: perceptive, material, technical, and conceptual" (p. 72). There are cuts made in the act of taking the photos, and not taking others. There are also cuts made in 'cutting out' some photos from view while 'cutting up' the environment by introducing others. Although the language of 'cut' carries a particularly harsh tone, I think it is useful way of thinking about the way families actively making their photos visible to others or making them invisible.

While I find Kember and Zylinska's writing on photography refreshing and necessary, it still moves us towards an ontological argument that I am not interested in following through in this current work. My aim is not to rethink the ontology of photography but to shed light on the way in which Bazin and Sontag are in fact confusing ontology with phenomenology, meaning they conflate an experience of photography with a statement on its being. They overlook the specificities of the lived experience of photography as inter-action and photographs as material cultural objects. These writers also ignore the dynamic range of experiences one can have with various photographs depending on how they make meaning of the photograph's production—its relations—and the circumstances of their own seeing. In other words, the way in which photography and photographs appear in our lifeworld is dismissed in the interest of identifying photography as a medium of death and frozen temporality, like so many

others have done (Walter Benjamin, 1931; 1936; 1940; Eduard Cadava, 1997).

Geoffrey Batchen (1997) has identified the contrast between formalist critics who assign fundamental characteristics to photography versus postmodern critics who challenge this essentialization. My own work aligns more closely with the latter, allowing photography to be "regarded as a dispersed and dynamic field of technologies, practices, and images" (Batchen, 1997, p. 5); I regard the Foucauldian-inspired work of art historian John Tagg as excellent examples of this approach (1993; 2009). To exemplify the value of a more dynamic approach that moves away from ontology, I offer a provocation: Is there an essence to the photographic medium that makes the images from Abu Ghraib prison (which Sontag critiqued in her later work) indistinguishable from the images her life partner Annie Liebovitz took of Sontag's own dying and then dead body after Sontag succumbed to cancer?[13] Phenomenologically speaking, I contend there is no such essence and that it is ethically dangerous to analyze photographic communication based on this assumption of ontology. In photographing her dead lover, Liebovitz was entering an intercorporeal relation with Sontag's body that exceeds the image it produced.

Although arguments based on indexicality and the photographic trace fell out of fashion when digital technology problematized the notion of photographic realism (Yacavone, 2012), the equation of photography to death has been tenacious. I account for this remnant with the argument that there is no analogue trace needed to think of the

[13] Sontag's essay "Regarding the Torture of Others" is here: www.nytimes.com/2004/05/23/magazine/regarding-the-torture-of-others.html and Liebovitz talks about her decision to take and later publish the photos of Sontag here: www.nytimes.com/2006/10/06/arts/design/06leib.html?pagewanted=all

camera as a medium that shows what is past or has passed, yet it is such a concern for temporality that remains in photographic theory. In fact, I would argue there is an over-emphasis on temporality and an overlooking of space in some photographic theory. For example, although well aware of digital technologies, Vivian Sobchack's *Carnal Thoughts: Embodiment and Moving Image Culture* (2004) still holds that "the photographic has something to do with loss, with pastness, and with death, its meanings and value intimately bound within the structure and aesthetic and ethical investments of nostalgia" (p. 146). She concludes that unlike "the cinematic" or "the electronic," the photographic "Functions to fix a being-that-has-been" (p. 146). Though she does not reference Barthes in this quotation, Sobchack's phrasing clearly rings of the "that-has-been" quality Barthes ascribes to photographs. What becomes obvious is a bias towards temporality, not only in photography but also in the corporeal subject's lived experience of space-time. To counter this bias we must recognize that photographs do not simply capture a moment that has past, they communicate a space that is "under construction" (Massey) as bodies and objects came together to shape that space across duration of time. The act of photography is one of many interventions into and inter-actions within that space, but is also the one that re-presents—makes present—a specific and limited configuration of that space-time in the form of an image. Again, I am not invested in playing out this idea through ontology. I am interested in how we can critically analyze the use of photography in specific sociocultural contexts if we free the camera medium from pastness and death to allow people's lived experiences to come to the foreground. In pursuing my research with these theoretical foundations, my findings reveal that

participants do not experience EOL photography or the photographs it produced exclusively as death, mourning, loss, or that-has-been. Even in a photographic practice involving death and dying directly, the "death mask" notion of photography did not hold up. As I discuss further in my findings chapters, the camera was experienced more as a medium of proximity, presence, connection, and creation.

My findings should be read with Margaret Olin's (2011) work on "touching photographs" in mind, which expands the view of photography from a visual practice to one of touch or "tactile looking." Olin suggests "the "touching" aspect of photography helps construct relationships and communities" and that "The significance of tactile looking… is that it is more act than reading: it produces more than it understands. In contrast, readings aimed at understanding rely on a visual conception of looking" (p. 3). This returns to my earlier mention that I have not approached either the embodied-hermeneutic of my analysis or the EOL photos themselves as texts to be read. While Olin's work is not explicitly phenomenological, she does acknowledge Merleau-Ponty's work on visual-tactile perception, acknowledging that for Merleau-Ponty "vision and touch are interchangeable in lived experience" and, quoting from *Sense and Nonsense* (1964), that it was scientific knowledge that separated our senses (Olin, p. 9). Merleau-Ponty makes his position on the visual-tactile explicit in *The Phenomenology of Perception* as well, as he says:

> Thus the connecting link between the parts of our body and that between our visual and tactile experience are not forged gradually and cumulatively. I do not translate the 'data of touch' 'into the language of seeing' or *vice versa*—I do not

> bring together one by one the parts of my body; this translation and this unification are performed once and for all within me: they are my body itself. (1962, pp. 149-150)

I also draw on Olin's counter-reading of *Camera Lucida* in which she again employs her concept of tactile looking:

> A reading of *Camera Lucida* suggests that the most significant indexical power of the photograph may consequently lie not in the relation between the photograph and its subject but in the relation between the photograph and its beholder, or user, in what I would like to call a "performative index," or an "index of identification." *Camera Lucida* allows us to see its narrator use photography to satisfy his desire to possess or commune with his mother, to absorb her into himself and preserve her there through his identification with her. Photography is a winter garden, like a *chambre claire* that lets in light in the winter and keeps alive artificially that which should otherwise have died. (Olin, 2009, p. 85)

It is the relational aspect of the photographic act to which I am drawn, as I see our corporeal experience of photographic gestures and objects as "chiasmic" and "intertwined" (Merleau-Ponty, 1964), as one that we touch and are touched by; there is not essence to how individuals experience that touching—as a scholar it is not for me to categorically define it as an experience of loss, nostalgia or violation any more than of closeness, celebration or love—but it can provide a helpful starting point for analysis.

With this theoretical background I mind, I have approached EOL photography as a photographic practice that emerged in the context of neonatal care and took shape in

certain ways within the structures of critical neonatal care specifically. I consider how care-providers have called upon the camera to intervene in the arrangements of critical care and how families have taken up that call and made their own interventions. When I deal with the move from film to digital technologies I am not posing this as an ontological nor a technologically determinist move. For one, I am not entirely comfortable with a mode of media history that takes the digitalization of photography to be a chronological certainty or a clean break between 'old' and 'new' media.[14] Instead, I am drawing attention to how different technologies have allowed care-providers and families to call upon the camera in different ways and to *do* different things with the photo-objects once the family has left the NICU space-time. This doing, phenomenologically speaking, is experiencing. In these ways, my work aligns with Batchen's sense of photography as a history of desires more so than a history of technologies. In *Each Wild Idea* (2001), Batchen begins his inquiry: "When…did the evidence of a desire to photograph begin to appear with sufficient regularity and internal consistency to be described in Foucault's terms as a discursive practice?" (p. 5).

A thorough archival investigation into EOL photography in terms of when it appeared as a discursive practice will have to be reserved for future work, though I make gestures towards its emergence in Chapter 4. I mention Batchen's work here, however, to signal the manner in which I see EOL photography through the lens of desire: What experience do the care-providers desire? What experience do the families

[14] Rather than review all discussions on defining 'old' or 'new' media, for a useful sense of the issue I refer to Wendy Hui Kyong Chun's "Introduction: Did Somebody Say New Media?" in *New Media, Old Media*, by W.H.K. Chun & T. Keenan (Eds.). New York: Routledge, 2006.

desire? What experiences do they desire for their newborns? What experiences do they desire to avoid? I use this language because it is productive, or perhaps because it is re-productive in the sense that it sees photography bringing experiences to bear. I mention this in part as a counterweight to the work that, rightfully, critiques various acts of seeing and visualizing as relations of objectification, reification or violation in terms of female bodies, fetal bodies and reproductive politics (Duden, 1994; Newman, 1996; Cartwright & Treichler, 1998; Oaks, 2000; Haraway, 2004; Rapp & Ginsberg, 2007; Taylor, 2008). While I do not dispute the value of these feminist critiques of visual culture, I do hope to contribute a study of photography within a biomedical setting that recognizes the complexity of power and resistance in visual-tactile practices born of attachment, joy, mystery, grief, and love.

3. CREATING THIS STUDY: EPISTEMOLOGY, METHODOLOGY, METHOD

"Our methodological and epistemological choices are always also ethical and political choices." (Harding, 2006, p. 156)

Building on the methodological background provided in the previous chapter, here I detail my engagement with other foundations of research: epistemology and method, which together I take to "provide the framework for planning, implementing, and evaluating the quality of qualitative research" (Carter & Little, 2007, p. 1316). In the sections that follow I first discuss the epistemological theories holding up this piece of research, which I broadly conceive in a feminist approach to situated knowledges. Second, I discuss phenomenology and the concept of embodiment to detail the methodological and theoretical frameworks. Third, I outline the study's method and protocol that were developed in a proposal approved by York University's Office of Research Ethics (ORE) and the hospital's Research Ethics Board (REB).

3.1 Epistemology: Situating Knowing

Epistemology influences key components of the research process, such as the relationship between participant and researcher, the way data and analysis are assessed, and how the researcher presents the work and understands her audience (Carter & Little, 2007). One's theory of knowledge also carries an "ethical weight" in that "[i]t is the basis for explaining the rightness or wrongness, the admissibility or inadmissibility, or types of knowledge and sources of justification of that knowledge" (p. 1322). Epistemological approaches are normative and bound to socio-cultural values of what

can be known, what it means to know something, what is worth knowing, and what knowing *does*. I am drawn to the work that has been termed feminist epistemology, often associated with science and technology studies (see Harding & Hintikka, 1983; Harding, 1986; 1991; Haraway, 1991; Longino, 1990; Fricker, 2006; 2007) precisely because it foregrounds the normative element of knowledge production. Broadly speaking, a feminist investigation of epistemic frameworks and traditions probes the social, cultural and political context of what is upheld or denigrated as knowledge, truth, and evidence. Such a probe reveals privileged positions of knowing and challenges their claim of abstract objectivity. Within cultural scholarship, such a challenge has been widely articulated through Haraway's (1991) figure of the "modest witness," the "specifically modern, European, masculine scientific form of the virtue of modesty" whose "subjectivity is his objectivity" (pp. 223-224). Haraway's aim in her work on feminist epistemology is not to turn away from any sense of a real world or to steep in deconstruction so thoroughly as to deny bodies, meaning, or the useful aspects of scientific inquiry, but rather to build a "usable doctrine of objectivity" (1988, p. 580). Haraway likewise does not conceive a strictly gendered mode of objectivity reliant on an essentialized feminine subject or dichotomous privileged/marginalized knowing, but rather calls on scholars to recognize that "[f]eminist objectivity is about limited location and situated knowledge, not about transcendence and splitting of subject and object. It allows us to become answerable for what we learn how to see" (1988, pp. 582-83).

The ethos of situated knowledges guided my development of this research project in a few interrelated ways. One was to acknowledge that my knowledge

production was not an abstracted ideal, but an embodied process largely constituted and made messy by the systems, structures and lived interactions within which it unfolded. More specifically, the hospital research setting was not simply a location to which I went to do research, but a spatio-temporal site producing me as a researching subject and my participants as researched subjects. I experienced the structure and rhythm of the institution positioning the work immediately upon beginning the research ethics process, which resulted in a document over 100 pages long and took one calendar year to complete. The study was shaped by the structure and demands of the ethics proposal, which was essentially a script for the research performance and a map of its boundaries. The ethics process positioned me as knowing subject but also made clear that access to participants would be granted based on my capacity to be spoken (or disciplined) as an object-agent of a certain mode of institutionalized interaction. The research is not a universal knowledge claim made from nowhere, it is made up of a set of relations embedded in the biomedical context of the twenty-first century hospital. This context is both meaningful for and a limitation on the story this research tells.

Epistemologically, the REB process meant the nature of my inquiry needed to be translated out of the critical sociocultural language within which I had first articulated the project for the University's review process, into a language resonating with the medical practitioners who would decide if the project moved forward at their institution. While I maintained a critical sociocultural framework within my analysis and theoretical assertions, the way in which we configure the research on paper does shape the way in which the research unfolds and how creatively (for lack of a better

word) we can engage participants as knowledge collaborators. Practically, the ethics review configurations translated into scripted interview guides, scripted correspondence with participants, protocol for handling data, extensive consents, scientifically vetted methods and methodology, identifying potential harms to participants, as well as potential benefits to participants and to society. The research, in other words, would be spoken within the discursive mode of the medical institution through such technologies as outcomes, risk, consent, disclosure, and security.

There is a striking complexity to carrying out qualitative socio-cultural research within institutions that largely function within the paradigm of Evidence-Based Medicine (EBM), a "hugely influential healthcare movement since its incipiency in the early 1990s" (Goldenberg, 2013, p. 13): "[I]nstead of relying on hunches, habits, and other subjective decision-making criteria, evidence-based decision-making relies on evidence, which, in turn, is supposed to support informed and unbiased reasoning" (p. 13). What this means in relation to my project, for example, is that despite decades of nurses' experience with taking photographs and building relationships with bereaved parents in ways that might inform their actions around grief support, institutionally structured and approved studies are required as 'evidence' before certain practices are put in place. Therefore, in many ways, structuring the project as a formal study with protocol approved by healthcare professionals through an REB process pulls the research (even if peripherally) into the EBM realm of positivist empiricism and potentially—though likely not unequivocally—allows for the translation of knowledge into practical application. A central tension in my research has been balancing the value

of this pragmatic translation with a commitment to a feminist epistemology aware of the power relations producing scientific rationality; this tension is also captured in my analysis, mirrored in the complex power/resistance of EOL photography that both challenges biomedical structures yet is also granted credence via the EBM studies identifying grief as a psychological state to be clinically managed. Thus, this study is shaped by EBM structures, yet acknowledges the conceptual baggage weighting down the assumption behind detached, universal evidence within the EBM framework (Goldenberg, 2005; 2007; Murray & Holmes, 2009).

Another way the ethos of situated knowledge guided this research's development is in the assertion that objectivity should be central to knowledge-production as long as it is understood as "particular and specific embodiment" (Haraway, 1988, p. 582). My epistemic focus on embodiment depends on a conceptualization of corporeal materiality that melds the thinking of Maurice Merleau-Ponty with that of Rosi Braidotti (1994). I bring together Merleau-Ponty's idea that the body is not an object but a continuum of relations *as* perception, with Braidotti's understanding of the corporeal "as neither a biological nor a sociological category but rather as a point of overlapping between the physical, the symbolic, and the sociological" (1994, p. 4). Braidotti figures the corporeal subject as the nomadic subject, a "political fiction that allows [us] to think through the move across established categories and levels of experience" (p. 4). In attempting to develop feminist epistemology while avoiding essentialized identities and normative traps, Braidotti proposes a nomadic consciousness that "aims to rethink the unity of the subject, without

reference to humanistic beliefs, without dualistic oppositions, linking instead body and mind in a new set of intensive and often intransitive transitions" (p. 31). Neither Merleau-Ponty's nor Braidotti's figurations contradict Haraway's situated subject, as all are located in space and time and, in their own way, "rest… on process ontology to posit the primacy of relations over substances" (Braidotti, 2006, p. 4). Situatedness, in my approach, is not about identifying geographical location or set positions, it is about mapping the often disjointed and fluctuating lines in the structure of relations that constitute knowledge-production. Epistemologically speaking, I conceptualize the dissertation itself less as a monument standing in for or signifying the research and more as a force or an intensity within the relations that emerge out of the research process. I see the research as a fluid network of social relations and embodied practices and interconnections—conversations, gazes, glances, spoken words, silenced words, attachments, flows, blockages, communion, fumbling, interpretations—that emerge *from somewhere in particular* but cannot be contained or reduced to a sum of parts. My authorship on the dissertation is thus neither a starting point nor an ending point, although, I recognize, the act of giving meaning through writing does carry its own responsibility. From the very first contact, a dynamic emerged between myself, participants, the hospital and the university, and will continue to evolve until our final contact; even then, both myself and the participants will continue to transition and transform in relation to this process. In other words, this dissertation does not simply document participants' experiences but is always-already in a relation of co-constitution with these experiences. It is worth noting that many of the participants articulated the

research process as part of their ongoing "healing" and their desire to "give back" to the communities of care-providers and bereaved parents with which they identify themselves.

3.2 Method: Study Design & Objective

The focusing question for my fieldwork research was this: How do parents experience EOL photography both in the NICU and as part of their life beyond the hospital? Because the objective of this qualitative study is to contribute an original experience-based analysis of EOL photography as it is carried out in a contemporary NICU setting, this research question was answered through a phenomenological method of data collection and analysis. I began with the Interpretive Phenomenological Analysis (IPA) as first modeled by Jonathan Smith (Smith, Harré & VanLangenhove, 1995), straying from its Husserlian roots (Biggerstaff & Thompson, 2008) to develop an approach based on the existential phenomenology of Merleau-Ponty, in community with other researchers who have built fieldwork around his philosophies of intercorporeality and intersubjectivity (Wynn, 1997; 2002; Schuster, 2005; Dahlberg, 2011; Guenther, 2013; Murray and Holmes, 2013a; 2013b). In addition to those building on Merleau-Ponty specifically, I also referenced research employing a hermeneutic phenomenology more generally; qualitative research into midwifery and childbirth proved particularly helpful for understanding the role of the life-world and meaning in phenomenological work. One example is the research of Ingela Lundgren, who conducted three long-term studies from 2005 to 2010 on how women make meaning of giving birth. Lundgren used what a

phenomenological method based on what she terms "a lifeworld approach," referencing the framework established by Dahlberg, Dahlberg and Nystrom (2008). In Lundgren's view, the lifeworld approach is based on the philosophy of Husserl and Merleau-Ponty, and

> seeks the patterns, structures and principles of the meaning of experiences, as well as unique experiences… The data analysis is described as a movement between the whole - to the parts – and back to the whole. During the whole analysis, the researcher moves from understanding the interview text as a whole, through understanding the single meaning units of the text. To a new whole, in which the essential meaning of the phenomenon is illuminated (Dahlberg et al. 2008). (Lundgren, 2011, p. 116)

In terms of embodied-hermeneutic, the interview-based research of Marja Schuster (2006) into nurses' self-understanding and their understanding of the patient provides an example of empirical research cognizant of subjectivity and embodiment—of both researcher and participant—in everything from data collection, to transcription, to analysis. In a later reflection piece, Shuster (2013) outlines "the complicity of subjectivity when interpreting texts" (p. 199) and "argue[s] that collecting, transcribing, and interpreting data can be understood as an embodied activity" (p. 203).

The conversational interview processes were intended to allow for responses that may challenge pre-existing assumptions about participants' experience with certain phenomena by bracketing common knowledge and focusing on the participant's open phenomenological description (Smith, Flowers & Larkin, 2009). However, my method

was also based on the tenet that all lived experience both shapes and is shaped by broader sociocultural conditions, using a double hermeneutic and the relying on shared, even if dynamic, language with the participants (Smith, Jarman, & Osborn, 1999). This means I also drew on symbolic interactionism, balancing the idea that individuals make meaning both from their personal worlds and their social worlds (Smith & Osborn, 2008). I further considered the phenomenological nature of the interviews as important to the participants' experience of the interviews themselves, as I understood the interviews as an embodied dialogue between myself and the participants, rather than as a top-down process starting with the researcher's expertise. The participants' knowledge around their own experience is a cornerstone of the interview (Kvale, 1996), as is the researcher's own embodiment (Sharma, Reimer-Kirkham & Cochrane, 2009).

I also integrated Photo Elicitation into my phenomenological design, which is the visual sociology technique in which photos are present in the interview to evoke different, more comprehensive, and often more profound reflections than just using text and spoken language (Harper, 2002; Radley & Taylor, 2003). The premise of having the photos present in the interview is that the researcher is able to see how participants' handle and interact with the photos as symbolic *and* material objects, rather than simply have participants refer to the photos through language. These embodied interactions with the photos were recorded in field-notes and analyzed along with the transcripts. Harper (2002) argues "the parts of the brain that process visual information are evolutionarily older than the parts that process verbal information. Thus images evoke deeper elements of human consciousness than do words" (p.13). As symbolic objects

"photographs can jolt subjects in a new awareness of their social existence. As someone considers this new framing of taken-for-granted experiences they are able to deconstruct their own phenomenological assumptions" (p. 21).

Welcoming the photographs into the interview process was also informed by conclusions made in a Norwegian study involving interviews with parents who had lost their child by suicide, SIDS, and accidents between July 1, 1997 and December 31, 1998. In an article reporting the findings, author Kari Dyregrov suggests that sharing mementos of the deceased allowed the interviewees to participate in shaping the interview process and forming "the necessary intimacy, trust, and understanding of what was conveyed during the interview" (Dyregrov, 2004 p. 397). This point was crucial since, above all, designing the study around IPA and Photo Elicitation was guided by the goal of creating a comfortable and effective research environment, fostering inquiry through dialogue while respecting the profound sensitivity of the topic at hand. In the initial scheduling emails, parents were invited to bring their EOL photographs as well as any other family photographs, images, or mementos they felt were meaningful to their family and/or their bereavement. These photos were for the participants to reflect on in the interview itself to bring new data to light that might not otherwise be revealed without visual images being present in the interview dialogue.

Primary data collection came from semi-structured interviews (carried out individually or as a couple), along with the participants' voluntary reflections on a summary of initial findings, as participants reviewed their own findings as part of the consented process. The interviews addressed the parents' experiences around the birth

of their baby, up to the death of their baby in the NICU when the photos were taken, and their experiences with the photos after leaving the NICU, up until the time of the interview. The study is not longitudinal and no follow-up interviews will take place. Although I had conducted a review of relevant literature before carrying out the interviews, I consciously attempted to structure my questions and conversation in a way that avoided leading language or simply circled back into conclusions made in existing literature, as was presented in the dissertation's literature review. The interview questions were also not meant to prove anything specific (either in support or against) EOL photography as a practice, but rather to gain insight more broadly into how parents made sense of this visual communication practice as part of their experience in this healthcare setting. While the fieldwork objectives were designed around knowledge production rather than clinical or therapeutic intervention, I recognized that the parents' participation in our dialogue and working through their own meaning-making had the potential to open new understanding around their grief and the role the photographs play in their lives; a number of parents confirmed this was the case, both immediately in the interview and after, which I discuss in later chapters.

i) Operational Definitions

- Newborn or neonate (used interchangeably): A baby who is transferred to the NICU after his/her birth at another institution and at death is a patient in this same NICU; the medical definition of neonate generally means a baby born at

>22 weeks gestation to 27 days of life.

- Newborn or neonatal death (used interchangeably): The death of a baby who is a patient in the NICU at the time of his or her death
- EOL photographs/photography: The process by which photographs are taken of a critically ill newborn throughout his/her life up until his/her death and/or shortly after. The photography can be carried out by parents, professional photographers, care-providers, friends and/or family, most often in the hospital but occasionally at home as well if palliation occurs there. All of the photos taken by the hospital staff are provided to the family as digital files on a DVD, as well as some that are printed. The professional photographers typically provide their edited photos on a DVD as well, with the option of posting some online or within a slideshow with music and graphics.

ii) Research Setting

The research setting is a NICU in one of Canada's pre-eminent hospitals offering neonatal care and comprehensive diagnostic capacity. This site was chosen because EOL photography is a long-standing and well-developed practice in the unit's standard of care around newborn deaths (of which there are approximately 80-100 a year in the NICU). This research setting provides tertiary/quaternary care for premature and/or full-term neonates with a variety of surgical and/or medical issues. The unit does not handle labour and birth services.

iii) Recruitment & Access

Beyond the initial literature review, which I outline in the previous chapter, the first step I took in completing this dissertation was to contact a NICU Palliative Care & Bereavement Coordinator. In discussing the value and viability of putting together a study about EOL photography, it was agreed the hospital's NICU would be an appropriate research setting. From there the Coordinator guided me on the REB process at the hospital. Once the REB approval was complete, potential participants were contacted by a written Invitation to Participate as part of the follow-up support information sent to parents who have experienced a newborn death in the NICU. This information is sent out in the Coordinator's follow-up in a printed and/or emailed bereavement newsletter at the annual anniversary of the death in the NICU. Therefore, the invitation to participate was only sent to parents who were approximately one year away from the time of the baby's death (as per inclusion criteria). Parents who were bereaved greater than one year, also had the information sent to them in a PDF if they were in contact with the Coordinator during the time of the study.

The first parents who responded to the Invitation to Participate were asked to fill out a brief Recruitment Questionnaire to determine they met the criteria to participate. These questions only pertained to the purposes of the study and were not considered to collect sensitive information. Parents who were not a match for the study based on their responses to this questionnaire were given a Decline-Response by email, and parents who were a match for the study were given an Acceptance-Response, in which the interview scheduling began.

iv) Interview Space

Participants had the option of interviewing in a private room at York University, Ryerson University, at the hospital, or at another location if they preferred. Home interviews were accepted or declined on a case-by-case basis after the researcher had made initial contact with the participants by phone. The rationale for not carrying out all the interviews in the participants' individual homes was my safety and comfort, as well as the participant's potential ease of having the conversation in a more neutral space. In the end, two interviews were carried out in participants' homes as per their request. Locations were offered outside of the hospital to all participants in anticipation of a return to the hospital being too emotionally difficult for many parents. When scheduling the interviews, only two of the respondents (as a couple) chose to interview at the hospital; in correspondence they suggested it would be nice to go back because they had many great memories there and wanted to visit some of the nurses they became close with through their stay. None of the other respondents chose to interview at the hospital, and two specified immediately in the scheduling emails that they would only do the interview if they did not have to go to the hospital, where they had not returned since the death of their newborn. I make note of these considerations around the interview space as a significant component of phenomenological interviewing. Facilitating the participants' choice in where to play out this interaction was one way of empowering them in the process by having the environment be as comfortable for them as possible. The significance of the interview space and impact of holding them in participants' homes was raised by the very first couple I interviewed for the project (whose responses

are not included in the findings because their newborn was born and died in another hospital). This mother mentioned after the interview that despite the inconvenience of traveling to the university she was happy she could leave the emotional residue of the interview behind rather than have it linger in her home.

v) Considerations for Joint or Individual Interviews

Another consideration made in putting together the interview protocol was whether to have participants interview individually or together in a couple. In reviewing existing literature on the advantages and disadvantages of interviewing participants alone or together, Taylor and de Vocht (2011) suggest that interviewing individually might mean "participants are more freely able to express their own individual views" without feeling they need to align or negotiate their perspective with those of their partner (p. 1577). At the same time, in joint interviews couples "can corroborate or supplement each other's stories. They can probe, correct, challenge, or introduce fresh themes for discussion that can result in further disclosure and richer data" (p. 1577). In the context of my specific inquiry I acknowledged there might be some aspects of the participants' individual experiences that they had not shared with their partner prior to the interview and therefore might be reluctant to disclose in a joint interview. I also recognized, however, that there might be emotional security in interviewing together and supporting each other through the process. Therefore, in the scheduling confirmation email exchange I gave participants the option of being interviewed separately or with their partner.

vi) Interview Process & Analysis

Once the interviews were scheduled, they were completed over a two-month period. Interview data was collected by a digital audio recorder and later transcribed for analysis. Accompanying field notes were also taken and analyzed together with the transcripts. While I initially planned on taking field notes during each interview, I found the action of breaking eye contact and taking notes too strange and uncomfortable in the moment, breaking the rhythm of the conversation and distancing myself from the participant with an overly clinical tone; therefore, notes were taken after each interview instead. All participants also consented to having me follow-up within a few months after the interview with a summary of initial findings.

Interpreting data within an IPA approach is understood as finding meaning in the language beyond mere description, analyzing each interview for theme, narrative, shared language, divergences, embodied reactions, and so on. My first step was to listen to each of the interviews for further immersion in the recording and take notes of an overall impression of the dialogue as well as audio considerations, such as tone, inflection, pauses, speaking style, emotion, etc. in the verbal responses. I then read the individual interview transcripts annotating interesting or significant points in the dialogue in one margin of the document. These notes were cross-referenced with any field notes taken on the same interview to put together an impression of the interview as a conversation, written in a separate document containing an overall view of each interview. I then re-read each transcript annotating possible theme titles in the other margin, such as expressions that abstract the qualities of the data enough to relate it to

broader theoretical meaning, but also remain *in* the text with the participants' specific responses. This was followed up by another reading of the transcripts line by line as a micro-analysis of the language, highlighting words and phrases directly in the document. The initial naming and categorizing language remained flexible at this stage, as the meanings became increasingly clear and thorough with further analysis. In reading these initial notes, I came to "cluster" any themes that have connections between them, then give those clusters a definition and name as a "superordinate theme" (Smith & Osborn, 2008, p.72) with relevant transcript excerpts pulled out for support. From here I read through the individual interview data again for axial coding, meaning in consideration of interview data in relation to each of the themes developed in earlier steps to see if new information emerged. Themes were finalized for each interview individually, then read across all the other interviews to note both shared and divergent meaning across the participants' experiences. As Smith and Osborn have noted, "one needs to be disciplined to discern repeating patterns but also acknowledge new issues emerging as one works through the transcripts. Thus, one is aiming to respect convergences and divergences in the data—recognizing ways in which accounts from participants are similar but also different" (p. 73).

After analysis was complete, I wrote a concise overview of the themes and narratives found across the interviews. This summary of initial findings (containing no identifiable information) was sent to all of the participants, since all ten had consented to receiving it. Participants were invited to reflect on the summary of initial findings and send back any comments, although it was specified that even if participants had

consented to being contacted as a follow-up, they might not want to/be able to respond at that time, and there would be no obligation to send back reflections. In the end, three participants sent back either verbal or written responses, which I have incorporated into my findings as well. Despite this return, during the interviews all parents were curious about the life of the study itself, what the findings would be from other parents, and how the findings might be communicated to people outside the community of bereaved parents.

vii) Sample: Inclusion, Exclusion, Overview of Participants

The sample was based on the respondents to the Invitation to Participate who filled out the Recruitment Questionnaire and met the Inclusion/Exclusion Criteria (listed below). The phenomenological study was designed around an idiographic mode of inquiry, meaning it was looking for specificities amongst a relatively small, homogenous group of participants, as opposed to making generalizations across a larger population (Smith & Osborn, 2008). In total, 14 parents responded to the invitation; seven responded on the day it was sent out, two more responded the following week, and five more over the following three weeks. Out of these first respondents, two were not able to participate due to geography and one due to scheduling; two cancelled the interview the week of because they felt it was too emotionally difficult to attend (though in one case the respondent's spouse came for the interview instead). The final sample included 10 participants, which was determined to be an appropriate sample size for a phenomenological study of this scope; 10 participants was also determined to be the

saturation point, as many of the key themes and language were significantly consistent across the participants, with divergences noted as meaningful in analysis as well.

Of the group of potential participants receiving the invitation to participate, exclusion from the study was based on the following criteria:

- Have not experienced the death of their baby in the specified NICU
- Have not had EOL photos taken by nurses in the specified NICU
- Have experienced the death of their baby earlier than one year from the interview time
- Have experienced the death of their baby greater than 5 years from the interview time
- Who do not speak English
- Cannot arrange for their own travel to the GTA

In the end, the sample was constituted as follows:

- Four fathers and six mothers; of the 10 participants three mothers and two fathers interviewed individually.
- Participant age ranged from 29-years-old to 44-years-old
- Five participants self-identified as originating from Western Europe, Eastern Europe or Asia; Five participants self-identified as Canadian, with two self-identifying as Canadian, originating from another country
- Eight participants self-identified as married; two self-identified as divorced or separated
- Two participants had college degrees or diplomas; Six had university degrees;

Two had post-graduate degrees

- All participants had photos taken by nurses or themselves in the same hospital within last five years. Four of the participants had EOL photos taken by a professional photographer, in addition to pictures taken by nurses and themselves. Five of the participants had other young children when their newborn died and two had another child after the death of their newborn. For two of the participants, the newborn who died was survived by a twin.

I also conducted one preparation interview with the Coordinator to get a basic understanding of how EOL photography is carried out at the research site specifically and background on the development of the practice in this NICU.

viii) Limitations

It should also be noted that the necessity for English-speaking participants and for all interviews to be held in the GTA were based on a lack of funding for researcher travel outside of the GTA and a lack of funding for translation services, respectively. I recognize that both factors might impose limitations on the final sample demographics in terms of limiting the research to English-speaking participants who are proximate to and/or able to travel to Toronto's urban center. Likewise, the research setting itself as a highly developed tertiary care facility may present quite disparate experiences than smaller or more rural hospitals. One goal of future research will be to build on the initial insights reported in this dissertation by including broader populations in further studies. It would be incredibly valuable to expand research to include a diversity of perspectives

amongst the participants to account for the many ways sociocultural factors are woven into the experience of neonatal death in general and EOL photography specifically. It might also be helpful to talk to families who chose not to participate in EOL photography, regarding their decision in the NICU and their experience without the photos beyond the hospital. As is, this study does not capture any findings regarding families who chose not to participate and/or who did not choose to have EOL photos taken.

ix) Data Management: Confidentiality & Consent

The interview MP3 files and de-identified transcripts are stored securely at the hospital on an encrypted USB key. The signed consent forms are also stored securely at the hospital, separately from any other data. The brief demographic questionnaire (containing no identifying information) is also stored on site at the hospital. While the Coordinator sent out the Invitation to Participate and provided valuable guidance in developing the study's proposal, the Coordinator has not been made aware of who participated in the study (unless parents chose to self-disclose) and has not accessed any identifiable information at any time. This measure was taken in the interest of protecting participants' confidentiality and their comfort in providing open and honest answers about their NICU experience, since I am a researcher positioned independently from the hospital.

All participants gave written consent to a) participate in the research, b) have the interview audio recorded, c) have basic demographic information collected to provide

an overview of who participated, and d) to be contacted after the interview with a summary of initial findings. The consent forms were handed out and explained to participants at the beginning of each interview, along with a Resource Sheet containing contact information for various organizations that work in bereavement support in case participants felt they needed to talk to someone after the interview. Eight of the 10 participants gave permission to reproduce specific images of their choice for various research publications, including this dissertation. Nine of the ten participants also chose to waive anonymity. A number of the parents are active in the bereavement community and understood their participation in the study as part of their "giving back" either to the hospital that took care of them and their newborns, or to the families in general who might be experiencing this profound loss in the future. In this case having their name associated with the study was not unlike having their name associated with the other work they did in the bereavement community. Another consideration for waiving anonymity was to allow the names of their newborns to be included in the publications that come out of the study. One couple who had not originally signed either the image reproduction consent nor waived anonymity ended up changing their minds and re-signing for these things. As the mother articulated after reading the summary of initial findings, it felt strange to read about the other parents' experiences without the babies names included. The mother likened it to how naming the baby in pregnancy is important to imagining who the baby is; as the interviews very much recorded the newborn's life and death story, a generic 'him' or 'her' or does not quite feel the same. I have left baby names in any interview excerpt included in the proceeding chapters, if

the excerpt is from a parent who consented to waive anonymity.

x) Research Ethics

All protocol was approved by York University's Office of Research Ethics and the Research Ethics Board of the hospital site. The hospital ethics review process entailed review and approval by a Science Review Committee, the Neonatal Division, and the Research Ethics Board.

4. FINDING EOL PHOTOGRAPHY IN THE CONTEMPORARY NEONATAL INTENSIVE CARE UNIT

Following the data management protocol laid out in my Research Ethics Board proposal, all of my data has been stored securely on site at the hospital throughout the study. While completing my fieldwork, after each interview I would immediately carry the digital audio recorder to the hospital, bring it to the confidential transcription services, and wait for an email weeks later letting me know the de-identified transcripts were complete and available along with the original MP3 audio file on an encrypted USB.[15] I would return to the hospital to retrieve the materials from the secure location in which they were stored, then spend many hours there immersed in the sounds and words of the interviews. My physical presence at the hospital when working with the data inevitably impacted my research process. Being there was a constant reminder that research is not objective reflection, but a fully embodied process, as many scholars have recognized and campaigned for (Sandelowski, 2002; Ellingson, 2006; Sharma et al., 2009). My days were filled not only reading the transcripts, but sitting in the cafeteria amongst patients and their family members who had probably not eaten anywhere else in days, moving out of the way to let nurses and doctors shuffle past with purpose, hearing emergency codes called across the sound system to mobilize teams, watching small children tote their IV bags along like a friend they both need and resent, waiting to see the seasonal decorations adorn the hallways to brighten the space and connect it to the rhythms of the outside world. It was impossible not to merge these noises,

[15] Only one interview took place at the hospital. For the other interviews I would travel to the hospital immediately after the interview was complete to deliver the recording to the transcriptionist.

movements and sights into my work, just as it was impossible not to bring my reading of the data to life through my experience in this place.

Continually returning to my participants' site of experience made it impossible for me to abstract our conversations as 'data.' For instance, in one of my first interviews, a father mentioned that months after his son died he attended a fundraiser meeting for a paediatric organization for which he volunteered. The meeting began with a short video about the hospital and showed footage of the lobby elevators. The father recounted how upon seeing the elevators he "felt like he had been punched in the stomach" and "started crying":

> I had a reaction like that just to see the building and remember the days, the constant visits there… the elevators that we rode so many days nervously looking across the window wondering 'How is he doing? How is the treatment? Is he getting any better?'… These were all the things you sat and thought of on the little elevator ride up while looking across, because [our son] was right against the wall inside the window.

Every time I rode those same elevators after this interview, I could not help but think of this father and his wife being lifted through the air, running these questions in their heads before they reached their son's incubator every day. Imagining the experience he had recounted as well as the pain caused just by catching a glimpse of the elevators in a video months later provided valuable insight into the profundity of what it means to look at photographs from those times and places, not only alone in their own homes but with me in the interviews as well.

At another point in my fieldwork, I was waiting in the hall outside of the neonatology unit when a young couple walked out of the private room provided for parents to spend time with and care for their newborn. The mother cradled her very tiny newborn as the father walked slowly beside her down the hall. Following them was a photographer who snapped as they walked, in a similar manner as reportage photographers follow a wedding couple, leading them to a large, bright window to take more photos in the pouring light. I immediately thought of all my participants who had at one point been in front of the camera in one way or another, just like this couple walking past me with absolute focus on the little person in their arms despite the camera moving around them. This moment and every other moment I spent working in the hospital helped me situate my participants' experiences. Being in the hospital brought to light the specificity of *that* place—the place parents had once arrived at bewildered, through which they had waited, wandered and wondered, and eventually from which they left without their newborn. To be clear, my work was not ethnographic in any way; the parameters of the study did not include spending any observational time in the neonatal unit itself. My point, rather, is that being aware of the hospital in my own experience as a researcher helped make clear the horizon upon which the phenomena of EOL photography came to be foregrounded in my analysis.

The sparse cultural literature on EOL photography to date writes an uncomplicated origin story connecting the current practice to a nineteenth-century camera-based memento mori custom. Problematically, this understanding abstracts the photography as timeless and transcendent rather than as a sociocultural practice

embedded within material relations. Part of my study's work has been to counter these abstractions in order to surface the phenomenological dimensions of the photography, while feeling out its social, cultural and political contours as a media practice. Among other things, contemplating the spatial and temporal qualities of the parents' experiences brings to light the specificities and structures of a certain mode of reproductive health and death within which this photography takes shape; and in doing so, it becomes increasingly clear that it is not possible—or at least not helpful—to write a linear, unwrinkled history of EOL photography out of the Victorian era. For one, such a history mutes the disjuncture between a nineteenth-century photographic custom largely carried out in the home and a contemporary photographic practice carried out within the biomedical space of the neonatal intensive care unit. Because there is no phenomenologically-based research on how parents might have experienced mourning or post-mortem photography centuries ago, I will not make any conclusions on how their experience might compare with contemporary parents. Rather, throughout the dissertation I look to my findings that locate EOL photography in the NICU, not as a neutral background to a timeless practice but as a meaningful space. I begin this task below, focusing on the NICU as the spatialization of the power/knowledge that is critical neonatal care.

The first section of this chapter details some history of the NICU in terms of the institutionalization of perinatal and neonatal care. The intention here is not to achieve a timeline but rather trace a history of the present to round out a sense of the environment within which parents today are experiencing the death of their child. This also helps

illustrate the NICU as the space within which the "neonate" discursively emerges as a medical subject with unique needs and limitations. With this outline of the NICU and the neonatal subject in mind, the second section of this chapter then considers the emergence of the "bereaved parent" as another clinical subject to be assessed, tended to and treated. It was not until the discursive construction of the "bereaved parent" that bereavement support protocol was given logic within the NICU in the decades after neonatology was fully established as a medical field. Having said this, it is not my intention to dismiss the emotional labour that healthcare staff mobilizes in the interest of caring for parents who are experiencing the death of their newborns in the NICU, which is also central to the development of bereavement support. As other research has shown, the staff's incentive to develop bereavement support was not top-down but came out of their immediate interactions with parents who were clearly grieving but not being met with validation or compassion (Davidson, 2007). The institutionalization of these support systems, however, does rely in part on the clinical research that classifies "perinatal grief" as a psychological response in need of intervention. Here we see the permeable networks of experience that is both produced out of power/knowledge yet cannot be reduced to it. The chapter concludes by narrowing in on EOL photography as part of the bereavement support that developed in the NICU within the late 1970s and 1980s. I consider the complexity of the photography as a technology of power/resistance that on one hand subjectivizes the newborn body as "neonate" and the parent body as the "bereaved parent," while on the other hand materializes the in-between relations of death-in-birth that escape the biomedical apparatus.

4.1. Introducing the "Neonatal Subject" in the Specialization and Spatialization of Neonatal Intensive Care

One of the first outpatient dispensaries for sick children was established in London in 1769 by George Armstrong, but closed in 1782 due to lack of public support (Granshaw & Porter 1989, p. 184). It was not until the mid-nineteenth century that social values in Western Europe and North America aligned with the development of inpatient and outpatient care specifically for children. Granshaw and Porter (1989) suggest the rationale behind the European and North American colonial model of children's hospitals in the nineteenth century emerged out of the desire for "public protection of children on one hand, and the interest of the medical profession in exploiting the children in the service of its new scientific orientation on the other" (p. 195); these authors make the point that

> the end or purpose of the children's hospital was never strictly bound up only in the effort to advance clinical knowledge, to teach students, and to cure diseases, but had as much to do with society's growing interest in its children as social resources, to be entrusted to medical care for individual and social survival. (p. 195)

The language of children as "social resource" emerging in the nineteenth century suggests a connection between procreation and social reproduction. I propose we can trace this connection through the "deployment of sexuality" within which Foucault identifies "four great strategic unities which, beginning in the eighteenth century, formed specific mechanisms of knowledge and power centering on sex" (1990, p. 103).

Amongst these strategies are two in particular that foreground human reproduction in the historical construction of sexuality as a domain of knowledge. The first is "the hysterization of women's bodies" in which the female body is thoroughly sexualized, pathologized, maternalized, and "placed in organic communication with the social body" (p. 103). The second is "a socialization of procreative behavior" in which fertility itself undergoes economic and political socialization (p. 104). In these two strategies, we see responsibility emerge as a tool biopolitically fusing the otherwise intimate activities of procreating and parenting to the social realm of population and social resource. A feminist reading of Foucault expands his work to acknowledge how the pathological and economically socialized state of being pregnant opens the female body to a differential power/knowledge we can identify as a unique intensification of discipline and security, normalization and normation. If, as Rabinow and Rose have asserted, reproduction is a "biopolitical space par excellence" (2006, p. 208), the pregnant subject is produced, moved around, mapped, touched, penetrated, and pushed out of this space in ways that cannot be presumptively bracketed within Foucault's Malthusian couple (1990). In other words, it is important to correct Foucault's under-theorization of the pregnant body in the crucial intersection of anatamo-politics (individual bodies) and biopolitics (population). Once we recognize responsibilization as a technique through which the living pregnant body holds the truth of procreation as a social value and biological function, it becomes difficult to ignore reproductive loss—or at least its prevention and control—as a key site for making the pregnant body productive and docile in service of the state's administration of birth and mortality.

Having said this, one reason Foucault might not have focused on pregnancy or fetal life within his work on sexuality is that while children were becoming recognized as social resources in the mid-nineteenth century and taken up within hospital care, unborn and newborn life was only beginning to fall under medical attention. At the time children's hospitals were being instituted in the US, Canada, and Western Europe, the majority of births were still happening in the home; the move from home to hospital in the US, Canada and the UK, for example, occurred quite slowly in the first few decades of the twentieth century, increasing by the 1920s and 1930s until the vast majority of births were in hospital by the 1950s (Oakley, 1994; Danzi, 1997; Mitchinson, 2002; Hanson, 2004). Because birth was not taking place in the hospital, newborn death was also not occurring there. Despite ongoing development in paediatric healthcare in the nineteenth century, the accommodation of babies was not immediately included in the mandate or structure of children's hospitals. In the Canadian context, one of the oldest paediatric facilities in the country, The Hospital for Sick Children in Toronto, was established in 1875 but "the opening of the first real accommodation for babies" was not until 1915 (Braithwaite, 1974, p. 65). Thus, one of the first steps to take towards a history of the NICU is to mark the differences between paediatric medicine in general from neonatal medicine specifically. This step brings us to medicalized pregnancy.

Before the hospital birth, medicalized pregnancy was taking shape through physicians' involvement in home births with man-midwives becoming more prevalent at births as early as the late 1700s in Britain (Hanson, 2004) and slightly later in British colonies such as Canada and the US (Leavitt, 1986). The focus of these interventions

prior to the twentieth century, however, was less on newborn survival and more on reducing maternal death in delivery. Hanson corroborates this point by turning to the *Treatise on the Theory and Practice of Midwifery*, written by Scottish obstetrician William Smellie in 1752. As one of the pioneering childbirth doctors of his time, Smellie

> articulated the golden rule which prevailed for 150 years: "The mother's life is always to be more regarded than the safety of the child." It is still the case that when there is a conflict between the interests of the mother and child, the mother's safety comes first, but the difference lies in Smellie's and his contemporaries' generally pragmatic acceptance of foetal death. (Hanson, 2004, p. 8)

The "pragmatic" element of this acceptance is likely based on the limited capacities for obstetricians at the time to detect fetal distress or complications in-utero, to induce or facilitate birth without the mother naturally being in active labour, or to intervene in ways that did not threaten fetal safety (McGrath, 2002). Unlike female midwives, "By law apothecaries, surgeons and physicians were licensed to use foreceps" (McGrath, 2002, p. 68) and their aggressive technique of pulling out the baby did not lend to fetal or newborn survival. Thus, the work of early obstetricians was to re-align their practice with survival instead of death, to develop techniques for intervening without causing death, and to make visible the unborn as living foetus (McGrath, 2002; Hanson, 2004). A visual culture develops out of this medicalization, as others have written about extensively (Petchesky, 1987; Newman, 1996; Mitchell, 2001; Taylor 2008), focused on

the mother as disembodied womb and the foetus as independent "patient" (Harrison, 1984). What also emerges is the pathologization of the pregnant body:

> The conception of the womb as pathological and therefore diseased made it easier to separate the foetus from the mother… This process, dependent upon visualisation, has taken effect in little more than two hundred years. The modern, industrial environment within which the foetus now exists is a territory that can be controlled. The biological body of the mother is merely a side-effect. A previously hidden, undefined, privately experienced interior world becomes a space opened up to medical scrutiny, a womb that can be monitored and managed. (McGrath, 2002, pp. 34-35).

Within the medical domain of "reproduction," the "pragmatic acceptance" of fetal death would all but disappear in the early twentieth century with the advent of antenatal or prenatal care as a clinical practice across many western European and North American countries. A seminal account of antenatal practice is found in a 1901 *British Medical Journal* article authored by Dr. J.W. Ballantyne. Ballantyne's introduction to antenatal care reflects the obstetric imperative of medical intervention throughout pregnancy, rather than solely in labour. The pathologization of pregnancy produces a pregnant subject who is doubly bound in the classification of her own (ab)normality and the unborn subject's (ab)normality. The disciplining mechanism of antenatal care puts forward an optimal way of being a pregnant body, playing out in the overlapping but distinct clinical and public health arenas in such things as fetal diagnostics or anti-drinking campaigns. One British physician working under the Medical Research

Council in 1921 articulated the matter as such:

> The ideal is antenatal supervision and care of every unborn infant by the compulsory, or preferably by the voluntary, notification of the pregnancy of every expectant mother… It seems illogical that expectant parents should be allowed to risk the life of their unborn child with impunity, whilst the failure to provide even for its physical comforts after birth renders them liable, and rightly so, to the condemnation of the law and of public opinion. (Browne, 1921, p. 145)

Browne's language of parents being *allowed* to risk the life of the unborn is nested in liberal notions of individual choice and the public good. Antenatal care addresses both the risk of misdirected lifestyle and the risk that all pregnancy carries as a pathologized state of being. Oakley (1984) has suggested this pathologization provided antenatal care with "its final mandate, a mandate written by the medical profession in alliance with the population-controlling interests of the state, and one giving an unprecedented degree of license over the bodies and approved life-styles of women" (p. 2). The clinical and technological shift towards "prenatal diagnosis and treatment" (Ballantyne, 1901, p. 815) also opens ground upon which fetal and newly born life can be addressed within clinical discourse as "patients" who require care in a specialized medical space, which the NICU was built to provide.

i) The NICU, the "Gray Zone" and the "Threshold of the Living Subject"

The medical interest in fetal and newly born patients depended on "temporal and bodily continuities across the divide of birth" conceptualized as the "perinatal threshold"

(Weir, 2006, p. 32). In simple terms, perinatal means *around* birth, intimating a temporal passage of the foetus in utero to the newborn (the "neonate") after birth. Weir refers to this passage as a "zone of transition into and out of human bodily substance" that she terms "[t]he threshold of the living subject" (p. 1). While there is a clinical distinction made between perinatal and neonatal medicine, they overlap both theoretically and practically as the term "threshold" would imply; the passage between the unborn and the newly born is a temporality in itself, more so than a defined state of being. In terms of reproductive death, the perinatal threshold is crucial to thinking of unborn life as life-in-progress, developing from cells to embryo to "viable" life that can survive outside of the mother's womb. While Weir looks at prenatal care and perinatal mortality as the main clinical and epidemiological sites of the governmental "health complex" (p. 32) targeting fetal death through the technology of risk, we must also consider neonatal intensive care as the medical trenches within which practitioners fight for newborn survival when risk morphs into outcome. The "limits of viability," as clinicians term it, are technologically stretched and marked within neonatal intensive care. In many ways echoing Weir's language of the "threshold," perinatology and neonatology reference the concept of the "gray zone" in defining the limits of viability. In a 2008 article reporting a review of literature on "survival and long-term neurodevelopment outcome in very preterm neonates," authors Seri and Evans suggest "[o]ne of the fundamental challenges that perinatal-neonatal medicine has had to address from its inception is to define the level of maturity below which survival and/or acceptable neurodevelopment outcome are extremely unlikely" (p. S4). Based on their

literature review they conclude:

> Most clinicians and investigators agree that applying the concept of the 'gray zone' is best suited to define the limits of viability for the most immature patient population. Below the lower limit of the 'gray zone,' the infant is too immature to have any reasonable chance for survival without severe deficits. For these infants, provision of care other than comfort care is unreasonable. Above the upper limit of the 'gray zone,' however, the infant is mature enough to have a reasonable chance for a good outcome, therefore initial aggressive care is the norm, at least until the patients' response to treatment can be objectively assessed. For patients falling within the 'gray zone,' careful consideration of certain additional factors and constant reevaluation of the effect of the treatment in the delivery room and later in the neonatal intensive care unit (NICU) are recommended. (p. S5)

Once the newborn patient's weight is seen to fall within the gray zone, the NICU is the space within which this "initial aggressive care" is carried out. Distinct from obstetrics or fetal medicine, neonatology was formed around the 1960s as a medical specialization that discursively produced the neonate. The NICU differs from a general obstetric ward due to the former's mandate to admit premature babies who are healthy but under the necessary weight for release, as well as full-term or pre-term babies with congenital anomalies, acute illnesses, or surgically correctable abnormalities; these cases are transferred out of the maternity ward to neonatal intensive care units within or outside of the birthing facility (depending on the individual

hospital's resources) when it is determined that more extensive or specialized diagnosis or treatment is required. Not all NICUs are the same at every hospital, but have different capacities depending on whether they are Level 1, Level 2 or Level 3.[16]

Level 3 NICUs in particular, such as my research setting, do not simply act on or respond to the gray zone but in fact sculpt its edges; here both living and dying are administered within complex modes of biomedical intervention that carry bioethical weight unique from adult care. Life and death intertwine in the NICU through intense intervention before, during and after birth. Technoscientific innovation has vastly improved the survival rate amongst newborns of increasingly low birth weights, meaning newborns who would have been far outside the limits of viability decades ago are now delivered, kept alive and treated with much more hope for short-term if not long-term survival. For example, a study by Kaiser, Tilford et al. (2004) of 4878 very low birth weight neonates (VLBW; defined as birth weights of 501g to 1500g) born in a public hospital in Texas from 1977 to 2000 indicates that survival rates have "improved dramatically since the introduction of neonatal intensive care." The study indicated that the rise in survival correlated with a proportional rise in VLBW neonates receiving ventilation from 59.0% to 80.9% (p. 343). Part of what this finding reveals is the way in which much of the work in the NICU is targeted at simply maintaining the baby's vital signs in order to carry out further diagnoses, treatments or surgeries as needed. For this reason, the NICU has a particularly solid dependence on technological and

[16] Level 3 are tertiary care units that handle the most critical cases. There are 21 Level 3 NICUs across the Canadian provinces and territories, including my research site. http://cnsfoundation.blogspot.ca/p/canadian-nicus.html

pharmaceutical interventions even in its routine care.

Generally speaking intensive care is designed to delay death in order to return the patient to a stable if not optimal condition, but in neonatal intensive care even the patient's 'stable' condition is especially precarious because of the tiny often prematurely developed system that is undergoing treatment. What this means is that some deaths are still inevitable in the NICU and that "[m]ost of these deaths follow decisions to limit or withdraw intensive care," upon consensus between families and physicians (Wilkinson et al., 2006, p. F270). There has been much research from within many national contexts into how parents experience these life-and-death decisions and how difficult it is to decide when to withdraw or continue with treatment (Pinch & Spielman, 1990; Kavanaugh, 1997; McHaffie, Laing & Lloyd, 2001). One such study "based on 20 qualitative interviews of Norwegian parents who experienced life-or-death decisions concerning their premature and/or critically ill infants" (Brinchmann et al., 2002, p. 397), connected the challenges parents face to the technoscientific setting within which the parameters of these decisions are set. Based on their findings, the authors suggest contemporary "neonatal medicine in particular is distinguished by uncertainty and ambivalence in some situations":

> Technological developments in neonatal medicine sometimes lead to prognoses that were previously seen as being very poor, as being experienced as increasingly uncertain. This again means that, in some situations, it is very difficult to judge which infants should be treated and which should not. (p. 401)

Before innovations in neonatology, the limit of viability was low and involved fewer

treatment options and therefore less decision-making. With more extensive intervention, however, the potential for survival increases along with the need to determine a course of action. The biomedical apparatus that makes unborn or new born life more "viable" also constructs life as the absence-of-death, with machinery that can be kept on (living) or turned off (dying); the bioethical weight of deciding when these states of being transition into each other is intense to bear for both parents and physicians.

Although Clarke et al. (2010) periodize biomedicalization in the 1980s, I argue the technoscientific and bioeconomic foundations of neonatology clearly signal the discipline as a biomedical knowledge appearing before the 1980s. Neonatology's "golden age" has been dated to the 1960s and 1970s (Lantos & Meadows, 2006), due to the development of a number of key innovations allowing for increased survival rates and more efficient and accurate diagnoses. These innovations include: the facilitation of biochemical measurements, mechanical ventilation, cardiopulmonary management, and the development of Total Parenteral Nutrition (TPN), which allows for sufficient nutrition to move through premature intestinal tracts (Philip, 2005). Hospitals prior to the late 1960s and 1970s could not adequately deliver the interventions required to increase the limits of viability to this extent, which provided the impetus for new infrastructure, around-the-clock attendance and the mobilization of vast resources that would result in the contemporary NICU (Lantos & Meadows, 2006). The discourse around the NICU's development is notably economic, with some suggesting the mobilization of existing resources "was not a scientific problem to be solved by more studies. It was a political and economic one to be solved by lobbying for alternative

methods of resource allocation" (Lantos & Meadows, 2006, p. 30). This economic language appears again in Jeffrey Baker's (2000) article on the history of the incubator in newborn care, in which he shows how the technology was invented in the 1880s but not solidly integrated until neonatology existed as a more coherently specialized and spatialized framework for its use. On the move from invention to total system Baker states: "This phase of innovation requires the talents less of a scientist than an entrepreneur" (p. 327).

In a chapter from *Maternal and Newborn Care: Nursing Interventions*, an edited collection published by The American Journal of Nursing Company in 1973,[17] we see a response to the biomedical healthcare paradigm laid out above. The chapter's author is a professional nurse who taps into a growing critique of hospitals at the time for offering "impersonalized care to their patients" as "big business institutions" organized along a model of mass production (Hilliard, 1973, p. 1). The passage below describes Hilliard's observation as a professional nurse of a maternity patient moving through her hospital visit:

> This expectant mother, just like an automobile part, was placed on an imaginary moving belt. The belt slowed to a stop several times during the first stage of "production"—the antepartum period. At each of the stops someone was there to pass or fail her in urine, weight, and blood pressure inspections… But there was little evidence of a growing acquaintance between the mother and her inspectors. She either saw different ones each time or was not remembered by the ones who

[17] This *Maternal and Newborn Care* chapter I reference here is based on an article originally published 1967 in *Nursing Outlook* (15), pp. 33-36 titled "New Horizons in Maternity Nursing."

> had seen her before. Like the automobile part, she was being dealt with by impersonal faces as she progressed through the various stages of "manufacture" toward completion and refinement. (pp. 1-2)

Produced out of the discourse of economic structure, social resources, entrepreneurship, and biomedical optimization, the newly industrialized hospital space within which birth and death-in-birth were experienced was a model of efficiency and results-based healthcare. The survival of the neonatal subject was the NICU's goal, and the death of the neonatal subject was the moment at which this patient and his/her family fell outside the NICU apparatus. As Foucault reminds us, "power has no control over death, but it can control mortality" (2003, p. 248); it is for this reason, I argue, that reproductive loss was configured as a population problem and a matter of stabilizing mortality rates across the early twentieth century (Woods, 2010), but remained (in)visible as an individual grievable death within this same time period. From here it follows that parental grief in newborn death was not taken up by healthcare staff as part of their institutional role. Though research throughout the 1970s, 1980s on to today would come to show that parents were indeed grieving (Zabourek & Jensen, 1973; Furman, 1978; Peppers & Knapp, 1980; Forrest, 1983; Borg & Lasker, 1989; Hughes & Page-Lieberman, 1989), neonatology discourse did not at first include this experience of loss and thus neonatal space was not structured to acknowledge or respond to it. At this time, parental grief was neither acknowledged nor supported by healthcare staff, as mothers were often sedated while their babies were removed and disposed of without ceremony, communication or compassion (Letherby, 1993; Davidson, 2007).

Expanding on the history provided in my literature review, we can make sense of some of the findings from Peppers and Knapp's (1980) seminal study on perinatal grief in relation to the conveyor-belt reproductive health model Hilliard details above. For example, Peppers and Knapp found that "unyielding hospital staff and inflexible hospital rules often hindered the resolution of grief" (1980, p. 22). Mothers expressed how hurtful it was to be returned to an obstetric ward with other mothers holding their healthy babies, simply because the rule was that they be returned to this space. Their lactating breasts would often ache at the sound of the infants crying, yet they were not moved nor their emotional distress acknowledged. Many of the women reported having an "unsatisfactory relationship" with their nurses, obstetrician or paediatrician based on how few of the professionals "expressed much concern about the tragedy that struck these families" (p. 21). Pepper and Knapp expand:

> Those who did attempt to fill the role of counselor-consoler often said all the wrong things. Such expressions as "forget this child," or "you are still young enough to have another," or "you should be glad that the baby was normally developed," or "you now have a 'little angel' in heaven" are all examples of clichés that parents absolutely did not need or want to hear upon learning that their infant had died. (p. 21)

We find an example exactly this kind of language in a textbook titled *The First Day of Life, Principles of Neonatal Nursing* (1970), written by the Grace General Hospital's (St. John's, Newfoundland) Chief of Neonatology at the time. The author instructs nurses on interacting with parents of a sick newborn:

> When a sick newborn dies the doctor should be the one to tell the parents but this duty sometimes falls to the lot of the nurse. What you say should be prefaced by, "I'm sorry to have to tell you this but your baby has died." You should expect tears from the mother and it is better to wait till the first flow is over before giving too many words of comfort. Often the first thing she will say is, "Well, that is the best thing that could happen in the circumstances." If she doesn't say this, then the nurse should at sometime suggest this idea… it is easier to tell parents about the death of a baby than it is to explain to the parents of a mongoloid child, for instance, what lies ahead. (p. 104)

What we see between this passage from 1970 and Hilliard's passage above from 1973 is that a certain shift was taking place in how neonatal staff were approaching not only the neonate in their charge but the neonate's parents as well. Neonatal nurses in particular began questioning the kinds of services they offered families from pre- to post-natal care, with an "emphasis… shifting to thinking about pregnancy-childbirth-newborn phenomena as part of a far larger process of family formation and growth" (Browning & Lewis, 1973, p. vi). As this emphasis moved from innovation to protocol over the last decades of the twentieth-century, a model of care developed that has been termed Relationship-Based Care (RBC) and/or Family-Centered Care (FCC). The "relationship" in RBC refers to two main relationships—"that of the parent and child… and that of the clinician and family" (Keefer et al., 2009, p. 205)—as well as that between the clinicians and their colleagues, as care-givers also grieve and require support when a newborn patient dies (Davies, Clarke et al., 1996; McGrath, 2011). FCC

likewise aims to foster relationships between the family and clinicians and "is based on the recognition that there are, in effect, two patients—the child and the family" (Homer et al., 1999). Today, both RBC and FCC are standards in contemporary paediatric care.

Within this shift in approach towards relationship-based and family-centered care, nurses were starting to push for acknowledgement and support of reproductive loss in the hospital setting as a foundational aspect of their relationship with families. As NICU advancements progressed and the critical care regime was further sedimented, nurses became aware of the gaping divide between the emotional distress parents were expressing and the cold response the system was set up to provide (Davidson, 2008). Of course in terms of the development of bereavement protocol in the service of relationship-based and family-centred care, it must be said that institutional changes require more than the anecdotal relay of nurses' experiences. These experiences were translated into institutional practice via the legitimation of clinical research that identified the grieving parents nurses spoke about, thereby producing the bereaved subject as one at psychological risk and requiring expert intervention. As early as the 1960s, perinatal/neonatal grief was being conceptualized within a clinical framework interested in its impact and potential treatments (Solnit & Stark, 1961; Cain, Erickson, Fast, & Vaughn, 1964) and the identification of psychological stages, expressions and outcomes of perinatal bereavement were being established (Leon, 1986; 1992; 1996; Peppers & Knapp, 1988; Toedter, Lasker & Alhadeff, 1988; Engler & Lasker, 2000). Clinicians and counsellors set out to develop interventions for supporting parents through their bereavement both in the hospital and ongoing, with the goal of resolving

grief and avoiding "morbid grief reactions" (Cullberg, 1971). Along with more personal interactions with parents, sensitivity training and the provision of counselling resources, neonatal/perinatal research also produced such techniques as the Perinatal Grief Scale, which was developed in the 1990s as a "common measure" of "grief scores" amongst bereaved individuals (Toedter, Lasker & Janssen, 2001). I highlight these clinical dimensions of grief here to consider the complexity of bereavement support as both medical intervention and emotional labour. The interstices of these realities play out in EOL photography as one of the practices initiated in the service of bereavement support, which I turn to now.

4.2 Building Bereavement Support into Critical Care: Between Bodies and Technologies in the NICU

Davidson's work (2007; 2008) on the development of perinatal bereavement support in Canadian hospitals from 1950 to 2000 draws attention to the context of the biomedical setting within which reproductive death was happening. As Davidson concludes:

> As pregnancy and childbirth were further medicalized and medical technology became high tech, distancing caregivers from the birthing women and their dead or dying babies, caregivers engaged in a countermovement of high-touch, repositioning themselves closer to the women and their experiences of grief in order to meet the women's social-emotional needs. (2008, p. 283)

What strikes me here is the spatial language Davidson uses to conceptualize bereavement support as a re-configuration of subjects in the biomedical space.

Davidson discusses the way in which medical technology distanced care-givers and families as well as families and their newborns, going on to say that "these caregivers imposed themselves between the medical technologies and their patients" and it was "[f]rom this proximate position, the caregivers first heard the women's stories and gave voice to their grief" (p. 283). EOL photography is a complicated example of one of the ways caregivers "imposed themselves between medical technologies and the patients" because it mediated the medical technology with another technology: the camera. Even further, the camera has often been conceived within a broader history of vision in western modernity that granted the "observer" status as "a subject of new knowledge and new techniques of power" (Crary, 1990, p. 79). As Jonathan Crary has argued within his history of "a modern and heterogeneous regime of vision," the "problems" of seeing and being seen are "fundamentally questions about the body and the operation of social power" (1990, p. 3). A thinker like John Tagg might argue that the meaning of the EOL photos were determined by the biomedical discourses within which the practice was given its logic through clinical research. Following this argument, the camera would be used in the NICU to affirm the neonate and the bereaved parent as subjects who are seeable, knowable and therefore governable. Sontag goes as far as to use terms like "predatory" and "soft murder" to describe the "act of taking a picture," claiming "To photograph people is to violate them, by seeing them as they never see themselves, by having knowledge of them they can never have; it turns people into objects that can be symbolically possessed" (1977, p. 14).

According to these frameworks, one might conclude that the "knowing"

achieved through EOL photography is simply a technique within the subjectivization of the bereaved subject and the neonatal subject. I want to complicate this assertion, however, by considering what Layne (2000) has called "the realness problem." In Layne's research on the taboo around pregnancy loss in America in the late twentieth century, she finds parents needing to "use the 'realness' of material things to assert their claim that a 'real baby' existed and is worthy of memory, and that they are 'real' parents, deserving the social recognition this role entails" (Layne, 2000, p. 322). Layne's conclusion follows that of other research confirming that the "validation" of the baby's life and the parent's grief are integral to the parent's healing and sense of social support (Limbo & Wheeler, 1986). So on one hand we have theories supporting the idea that the camera is used in the NICU as a part of the biomedical apparatus that turns individuals into objects of the clinical gaze. On the other hand, we see parents bereaved by reproductive death using the images produced by the camera to validate their experiences of joy, attachment, loss, and mourning that exceed the biomedical apparatus. Rather than assume the camera can only function within one way of knowing determined by the space within which it is found, I propose we think of the NICU as a space "under construction" (Massey) to consider how nurses and parents engaged camera technology to re-construct some of the structures of the NICU as biomedical space-time. Here we start with a different question in order to get at the phenomenological dimensions of the photography as something parents experienced rather than simply as a technology that was applied to them in the NICU: What were nurses and families calling on the camera to do?

To answer this question we have to turn to the technology itself, without assuming the function of EOL photography today can map precisely onto its function 30 or 40 years ago. The first thing to consider would be the camera technology being used when EOL photography was introduced versus the technology used today. One of the first pieces of equipment used in EOL photography was instant photography (for example the popular Polaroid camera), which allowed the nurses to provide a picture of the baby instantaneously to the families without outsourcing or waiting for processing.[18] There are many technical issues with instant photography, however, as Primeau and Recht (1994) documented in a comparison of instant photos to 35mm film photos that were taken at one institution as their bereavement staff moved from instant photography to film in the late 1980s and early 1990s. The problems they list with the instant photography are: that the photos tend to be "graphically clear," therefore "highlight bruises and discolouration" that cannot be manipulated after the fact; that no close-ups of details like hands and feet can be taken because the depth-of-focus is so narrow on an instant camera's lens, therefore the closer the camera gets to the subject the more it blurs; that instant photos are not printed on archival paper therefore the image often fades or cracks over time; and instant photography used colour film, while "black-and-white pictures are more forgiving than colour" and "helps hide or disguise discolorations and bruising, as well as some deformities" (p. 22). Ultimately Primeau and Recht conclude: "Both kinds of photographs validate the reality of the infant who

[18] Anecdotally, I have been told by a few bereaved families that some smaller hospitals still use instant photography because it processes the photo in-camera, and otherwise they have no extra grief support staff to process or print images.

died, but the professional photograph provides a softer, more comforting memory for parents and families" (pp. 24-25). Echoing the language from much of the training material from the earlier days of EOL photography, the emphasis is on the images being "positive" or "pleasant," as Limbo and Wheeler (1986) termed the aesthetic for which nurses should aim. The other emphasis is on the validation of existence, as we see in Gensch and Midland's (2000) historical overview of the Resolve Through Sharing program, which remains a prominent model for perinatal bereavement care in North American healthcare. Memory creation is a key facet in the Resolve Through Sharing standard of care and Gensch and Midland list photography as one of the "options and interventions [that] can be helpful in providing meaningful memories for bereaved parents" (p. 289). They write: "These pictures are invaluable proof of the presence of the baby. This may be the only tangible validation of the pregnancy for the parents to share with others" (p. 289). In this language of validation we see the discourse focused on the photos themselves as "mementos," implying a memorial function that marks the existence of a subject (the baby) and an event (the birth and the death). Therefore, although the photography was happening in the NICU, the nurses were using the camera to produce objects that would mediate the parents' loss after they left the NICU and were living their lives beyond the hospital without their baby. From the training materials and survey questions about "satisfaction" with having the photos taken at the time (see Laux, 1989), the focus is on the photos as meaningful objects more so than the act of photography as a meaningful relation between the nurses and the families.

We can return to the camera technology itself to contextualize this early focus

on producing a "positive memento" (Primeau & Recht). Beyond instant photography, 35mm film cameras were the main cameras used at my research setting from the outset of their bereavement program. The Coordinator explained that they started by providing families only a few frames each, since the film rolls and processing were costly. The film would be processed at a professional developer near the hospital with whom they had established a relationship and protocol for confidentiality; having the film professionally developed ensured it was properly processed with quality chemicals and printed on archival paper for longevity. Although better quality than a single instant-photograph, film cameras still limited the nurses to only a few pictures with the quality of the image often unknown until it was printed and the opportunity to take any more photos had passed. The Coordinator touched on the nurses' experiences of taking the pictures here as well, saying that many of them were nervous about their ability to take a good photo so would often snap the same picture multiple times in hopes of at least one of the frames having the right exposure. Also, knowing you only have a few frames to spare discourages taking too many chances on trying to capture action in a scene that might end up blurry either from the subject's moving faster than the shutter speed or from the photographer's own camera-shake. Therefore, when film cameras were the norm in the NICU, technical limitations steered the process towards capturing only a few key images, usually of the newborn on his/her own as well as a picture of the newborn with his/her parents in more posed portrait images. It is such images that Linkman (2011) connects to Victorian memento mori, saying of contemporary "post-mortem photography" in hospitals: "The aim of the new practitioners, like that of their

Victorian predecessors, was to produce a 'pleasing' or 'flattering' picture by introducing accessories such as flowers, using soft light or soft focus filters, and selecting suitable settings and poses… Contemporary approaches, however, deviated from Victorian practice around the issue of deformity and defects, where a degree of ambivalence was apparent" (p. 81). What does not hold, however, is the assumption that nothing has changed between this early approach to the photography as a memento-making practice and a more current practice; developments in both care practices and camera technology ought to be considered. I argue that digital technology facilitates a move from memento to narrative, which dramatically alters what nurses call on the photography to do within the NICU space.

To make this point, we need to bring together the limitations of film technology with the limitations created by the medical technology in the NICU, which the nurses are often trying to mediate in the first place. I put forward one common example that arose throughout my interviews, which is the fact that all of my participants' newborns were housed in incubators for the majority of their hospital stay. While the incubator was first designed as a technological method for temperature control, it has developed into a complex life-support system that is ubiquitous in contemporary neonatal care (Baker, 1996). While the necessity of the incubator to keep their babies alive was salient for all parents, the technology also physically distanced the parents from the newborns, despite intense desires to interact with and hold their babies. One mother recounted a story in which a midwife came into the NICU and placed a sign on the incubator that held her client's baby that read "I want to be held. Leave my mom alone," which many

of the parents in the NICU applauded. This mother agreed with the sentiment that parents were separated from their newborns too often by the equipment, so finally circumvented the policy around not holding incubated babies:

> One day I just said 'screw you' and I went in. Not the nicest thing, but because they make you wait and everything, I was not impressed, so I found a different way. So I had gone in, hung up my coat, I sat down and I gave them five minutes to come talk to me and then… I picked him up. They were like 'What are you doing?' and I'm like 'I'm holding my son because I want to hold my son.'

From a photographic perspective, the prominence of the incubator and other extensive medical equipment attached to the newborns means that it is difficult for nurses to get a "pleasant" shot of the baby that is close-up without the obstacle of the incubator and clear of the "wires and tubes," which many parents talked about and I will touch on in more detail in the next two chapters. Practically speaking, this means that nurses who are only able to take a few frames with a film camera are likely to wait until the baby is out of the incubator to capture the 'best' image of the baby in a portrait style without medical equipment dominating the frame. Clinically speaking, these moments outside of the incubator happen most often once the decision to withdraw life-sustaining technology has been made and the parents are holding the baby as she or he dies. In this way, early EOL photos were much closer to traditional memento mori photos in the sense that they were often post-mortem, either as the baby was dying in the parents' arms or immediately after when the nurse would take a few pictures of the baby after

the death, arranged delicately with special mementos as if sleeping, reminiscent of the Victorian style. Having said this, I do not mean to suggest the practice of photographing the babies around this process is no longer a crucial aspect of EOL photography, as it very much is. Eight of my 10 participants had photos taken around the time of life support withdrawal or in the moments after death and mentioned that the importance of these photos was the fact that they were taken during some of the first times the parents were able to hold the baby outside of the incubator and to have the medical equipment removed. What the interviews revealed, however, was that seven of the eight participants who had photos taken at the time of technology withdrawal had *also* been taking photos all along their baby's life from the time of birth to the time of death. It is worth noting as well that the one couple who did not have more than one photo taken around the death of their son, still had over 400 images from the months that he was living in the NICU, so they did not feel they needed pictures from that day in particular. What emerged here in a few of the interviews was a distinction between the photos taken directly around the baby's death or shortly after and the EOL photos taken across the baby's life and into their dying moments.[19] One father poignantly distinguished these two kinds of photographs as those of his son "living" versus those of his son "leaving," which I will return to in later chapters.

There are two points to mention regarding the "living" photos that parents were able to take home with them in terms of the shift to digital photography. One is that the accessibility of digital photography in D-SLRs, point-and-shoot cameras, or, notably, in

[19] I acknowledge as well that it is valuable to consider the differences and/or similarities that may arise between parent experiences in neonatal death and in other perinatal deaths, for instance when the only photos available for families are post-mortem and/or around death, such as in the case of stillborn babies. Further research would be helpful in this regard.

the cellphones that people commonly carry. The relative ubiquity of digital cameras compared to earlier film cameras means that EOL photography expanded beyond the nurses' offering to take pictures to the nurses' creating an environment in which families also feel comfortable taking pictures on their own. Rather than trying to guess what might be most important to capture for the parents, the families could either take photos with their own cameras or pick up the NICU camera themselves, feeling comfortable with a technology that was considered familiar and requiring less expertise than a film camera. This comfort is a sign of the camera's social position as a mainstream medium, present and familiar in contemporary life: "Arguably, over the last half century, photography has become so ubiquitous that our sense of being is intrinsically connected with being photographed, and with making sense of the world around us through seeing it imaged" (Kember & Zylinska, 2012, p. 76).

Second, the technical characteristics of digital capture and digital file storage allows for the taking, storage and access of a substantial amount of images. Digital memory cards allow for the storage of hundreds of images, far out pacing the average 12, 24 or 36 frame roll of film. Digital memory cards are also re-writable and therefore cost-effective for hospitals, because they are not one-use like a film negative. The preview screen built in to digital cameras also allows the photographer to see the image instantaneously and then to decide whether to re-take or keep moving with confidence that the intended image was captured or that elements like lighting and framing need to be adjusted. All of these digital features allow the person taking the photos more freedom in terms of snapping many photos in succession or across the course of the

newborn's life, which saves the photographer from holding on to the few frames they have for what they think is the optimal moment. The effects of these technical capacities are substantial in terms of the role EOL photography has come to play in the NICU.

I am not suggesting in any kind of technological determinist vein that the move from film to digital photography was responsible for EOL photography moving from a memento-making practice to a story-telling practice, nor that the camera caused the nurses' to see details that were otherwise invisible to the human eye—this is not a matter of Walter Benjamin's "optical unconscious" (1931). Rather, I propose that these technological shifts allowed nurses to use the camera to materialize different dimensions of their emotional labour and to call upon the camera to do something different than it had as a film technology in previous decades. The film camera helped nurses respond to the parents' existing desires to validate their newborn's life and death by producing a "pleasant" image of the newborn that families could hold on to as a way of showing others outside of the hospital that this life did exist. The film photography also often allowed nurses to take at least one or two photos with the parents, which then helped the parents incorporate this validated life into their own story as a family; this integration has been shown to be key to parents who feel their social identity as parents is lost when their baby dies (Malacrida, 1997). The technical capacities of digital photography then extended what nurses were able to offer families as the camera shifted from a tool for taking a handful of photographs to a tool for snapping many images in many different scenarios. By way of capturing moments from across duration of time in

the NICU, the newborn's life could be materialized within the narrative that families could construct out of the series of photos that were taken. The feel of the photos then moves from monument to story, providing parents more visual representations of their time in the NICU. My findings suggest these stories are often embedded within the gestures, movements and interactions that make up parenting and construct the narrative of the baby's life and death, whether this is a part of the withdrawal of life-sustaining technology or part of the parents' lived experiences within the NICU. The Coordinator's own language raised the idea that the nurses' role in EOL photography today is not limited to taking the photos for the families but also collaborating with parents in a story-telling process. A significant part of the nurses' work, as she said, is in encouraging families to take photos was "helping the family to frame what their world was like" in the NICU. In the Coordinator's spatially figured words, the photos provide a "place and a frame" for the experiences they have around the life and death of their newborn. In many ways the focus on helping parents locate their own memories and experiences brings to light the separation between the NICU and the outside world, to which the parents return after their time in the NICU, with no reference for friends and family to grasp what and where they had just been through. The Coordinator thinks of the photos as "the visual [that] gives [the families] the language for the story" they will share with others.

The digital technology further facilitates the care-providers' efforts to build relationships with the parents as well as encouraging more physical and emotional contact between the parent and the newborn, which I touch on further in the following

chapter. Phenomenologically speaking, the camera appears in the NICU as a medium of proximity and presence, not of displacement or pastness. Because the biomedical structures of the NICU position the bereaved parent's body at a distance from the neonatal body, care-providers have introduced photography as an intervention into this distance. The camera does not bridge this distance with a more 'human' touch that overrides medical technology such as the incubator, as the camera remains a technology itself; rather, photography as an embodied relation draws the nurses' attention to the parents not only as individuals who will leave the hospital bereaved and in need of mementos—or, the "bereaved subject" in need of treatment—but as individuals in the NICU who desire the opportunity to parent their newborn while he or she is living, no matter how few these opportunities may be across a short life. In addition to the role EOL photographs can play in maintaining "continuing bonds" (Klass et al.) and creating a "durable biography" (Walters) for the newborn, EOL photography is part of the *living relationships* parents experienced with their newborns in the NICU; this is the term I used in writing up my findings to umbrella the various themes in my data in which parents expressed a sense of "connection," a sense of "spending time," and a sense of "doing activities" with their newborn that was talked about as joyful interactions that should not be overshadowed by the experiences of grief they also endured. I will explain this further in the following chapter with a more in depth report of findings.

5. PARENT EXPERIENCES WITH EOL PHOTOGRAPHY IN CRITICAL CARE: LIVING RELATIONSHIPS IN NICU SPACE/TIME

What surfaced in the previous chapter was an image of the NICU as a complicated space intersecting a biomedical regime with practices of care and story-telling intertwined with *living relationships*. There are two themes from my findings which, when read in tandem, affirm this assertion through participant experience; when we read these themes together we get a sense of how disorienting lived experience within the NICU might be, as the parents' language evokes a description of a space that is both positive yet negative, clinical yet intimate, structured yet dynamic. First, a theme that stands out here is the way in which some of the parents talked about trying to glean information from the biomedical equipment in the NICU in attempts to make sense of their situation or to try to predict the outcome of their baby's future. One father shared the thoughts he would have as he approached the hospital every morning to visit his son, contemplating what he might be able to find out when he arrived:

> How is the treatment? Is he getting any better? The ventilator that he was on had different settings, depending on the oxygen levels… his O2 levels… have they turned it down a little, which would be a sign of progress that he was breathing better on his own, that he didn't require as much? You could typically… if not see his bassinet, then the bank of monitors and the different sounds that you typically connect with an NICU. You could often see the nurse. They stand at the bedside. They are there pretty much around the clock with the patients in the NICU.

In telling me their baby's story in the interviews, almost all of the parents took on medical diction with ease and some of their most coherent recollections were clinical

details and terminology. I noticed one family had taken many photos of the NICU space, which did not have any people in them but did show the machines, wires, and equipment. I asked the father about one of these photos and he responded:

> These are her vitals. We spent so much time looking at those. You look at those hoping and praying because certain numbers are good and certain numbers are not good. I spent as much time looking at that as I did her and just praying and hoping for better numbers. When I look back on that, it just seems so futile.

Trusting in their own interpretation of what the space was telling them, one mother felt her and her husband had to block out the "opinions and outside thoughts" that friends and family would offer because they did not balance with their own reading of the situation from inside the NICU; the language of "outside" is meaningful here, indicating her sense of the NICU in spatial terms and the distance she felt between herself and those who were not a immersed in the milieu. From inside the NICU, paperwork, technical details and clinical data translated to these parents' "knowing," as she touched on further: "Everyone kept on saying 'It's going to be okay, it's going to be okay." 'We were like 'No, it's not. We've signed two DNRs [Do Not Resuscitate]. We know.'"

A second theme I want to highlight and connect is the idea that despite what was often described as an overwhelming, chaotic, confusing, clinical milieu, some participants also referred to it as feeling "like home." In part this language comes from the length of stay that some parents had, living between their homes and the NICU every day for up to four or five months. Each of the parents mentioned their attempts to spend every day with their newborn when possible, though in some cases only one

parent could make it to the hospital when other children required attention at home or, in the case of multiples, a surviving twin required care in another hospital. It struck me when one couple lamented the fact that they had taken one day away from their son in the entire two months that he was in the NICU, despite the fact that they lived in a city an hour away from the hospital. Beyond mere duration, however, the language of "home" tapped into a certain level of comfort, care, warmth, and familiarity that parents feel in that space. The hospital appears as a place the parents wanted to remember to a certain degree, as many parents had also made a point of photographing common spaces in the hospital, the exterior of the hospital, in addition to the details and specificities in the NICU that they related to "being there." For instance, in one mother's photo album (a creative scrapbook that she put together on the first anniversary of her daughter's death), the first few photos in the album included a wide shot of the hospital, mimicking the common establishing shot in filmic narrative. Looking at these first photos she explained: "I just took a photo of [the hospital] because it was just like home for awhile. We were just there all the time." Around this first photo were other photos of the space inside, including details such as the equipment around her daughter's incubator, creative shots of the wires and equipment, and so on, about which she offered: "This is just again… familiar… We would go up the elevator and this is what we would see every day. It's like home again." Other families had also photographed some of the equipment, monitors and hospital rooms in general to capture the fixtures in their NICU environment, which was an important part of their experience and therefore something they wanted to document.

Through my analysis, it became clear that a significant aspect of the feeling of "home" within the NICU was produced out of (inter)actions between nurses and parents that were both spontaneous but also informed by the relationship-based care and family-centered care frameworks of neonatal nursing and neonatal bereavement support. What my findings below suggest is that EOL photography as a practice was an incredibly meaningful and substantial dimension of these (inter)actions, enacted as a collaborative process between nurses and families as an intervention into the spatio-temporal structures of the NICU. Part of the parents' lived experience in the NICU was intervening in the space through picture-taking, with emphasis on the 'taking' as an action implying making one's own or occupying. Sontag has said: "As photographs give people an imaginary possession of a past that is unreal, they also help people to take possession of space in which they are insecure" (1977, p. 9). While I agree with Sontag's sentiment, I would add that it is not the photographs at work here, but the experience of photography as an act that facilitates a sense of security or possession in a given space that is otherwise strange, disorienting or overwhelming—an act that makes meaning.

On one hand this picture-taking is a representational act as parents use the camera to capture the space-time of the NICU itself. They frame details and moments in the conventions of personal photography and insert these images into the narrative of a family photo album, the traditionally foundational means by which a family builds a story of itself (Hirsch, 1999). Even with this representational aspect in mind, however, I do not want to reduce the photography to the photos it produces but to conceptualize it

as embodied action unfolding in space-time. EOL photography—either carried out by nurses, volunteer professional photographers or the parents themselves—is not only visual, but more widely perceptual and erotic as Barthes might way (1980): it materializes intention and attention. Because the NICU is so 'other' than everyday life—so "elsewhere" to borrow a term from one of the interviews—photos taken in that space both allow parents to ground themselves in this immersive location and to transport parts of that space into their lives outside of and beyond its arrangements. To photograph the moments and details within the NICU is to enter a relationship with the space that informs the way in which parents experience its specificities, push against its structures and move forward when the time comes. The themes I present here from my findings focus primarily on the spatio-temporal qualities of the environment that both shaped and was shaped by the participants' experiences with EOL photography.

The first section of this chapter reports findings that suggest parents entered and endured the NICU in a certain state of "shock" within which they functioned as they were immersed into a regime of critical care for their newborn. In digging through the layers of this shock I unearthed feelings of "expectations" for a healthy pregnancy, labour and birth, and newborn baby that were overturned very suddenly with unanticipated health complications. These expectations related to a before/after temporality of reproductive loss, with the before being 'normal' pregnancy and after being a state of disorientation brought on by the realization of the fact that something "went wrong," as was heard in the interviews. As I illustrate with examples, the feelings of "shock" and "expectation" are key to understanding how parents made sense of

photography while in the NICU. Explaining this further through a slightly different lens, in the second section below I focus on "expectation" in terms of the anticipation of either recovery or death. I put forward that parents enter a complex temporal tension in which anticipation of recovery connected them to a future that is beyond the NICU, while anticipation of death sharpens awareness of the *now* of the NICU. The participants' experience in the NICU, then, was framed as a temporal passage into a future with their healthy, growing child who lives beyond the hospital walls or as bereaved parents who leave without their child.

In the last two sections of this chapter I turn to interview findings pertaining to the way in which parents interpreted photography in this space beyond their initial reactions and entry into the NICU. These findings add insight into the act of photography as an embodied (inter)action that both materializes and mediates key relations in the NICU: between parents and their newborns and between nurses and parents. I look at the relationship between parents and newborns in the third section of this chapter, and between nurses and parents in the fourth section.

5.1 "Shock": Experiencing the Unexpected

To begin each of the interviews, I would invite participants to tell me a bit about their family and to look through their photos albums if they had brought them. Each individual and couple I spoke to began by telling me the story of their son or daughter, usually beginning just before or just after their birth through to their death in the NICU. The conversations also meandered around to the parents' life and experience with their

EOL photos since their son or daughter's death up until the time of the interview. As these stories were told, my ear repeatedly picked up one word that seemed to echo through almost all of the conversations: "shock." I started to note the body language used when the word was spoken. It often entailed a widening of the eyes, a subtle shake of the head, or moving the head back as if being blown over. I was able to match these subtle gestures with the idea of "shock" conveying both acute emotional stress and a physical sense of being violently jarred out of a position, pushed against and moved by a severe impact, to have a current run through the body. In immersing myself in the data afterward, I noted the repetition of the word again, registering that it showed up multiple times in eight of the ten interviews. I then sorted through the transcripts to locate the exact context or evocation for the usage and discovered two main contexts. One was the parents introducing their birth story in regards to the "shock" or "surprise" of an unexpected pre-term birth or of the discovery that their newborn or unborn child was facing serious health complications. Another was the most common word used by the parents as part of their description of how they made sense of the nurses offering to take pictures or in their hesitation and/or inability to take photos themselves. The word was distinctly associated with their time in the NICU. They seemed to use it less as a singular adverb for their reaction to an event and more as a state of being within which they were trying to function as they moved through the reality—or "devastation," "chaos," "roller coaster"—of having a newborn in critical care. This immersive state of "shock" made their NICU experience a complicated mix of adrenalin-charged clarity and focus cutting through an otherwise muddy haze of over-stimulation and exhaustion.

One participant made a point showing me one photo in particular during out conversation, of him holding his child in the hospital. He singled it out saying: "I always look at that photo and realize that that was the best smile I could muster under those conditions." He used language like "so tired" and "so stressed" to describe his depleted state in those days, which he later said he had not restored from for months after. This state of being was presented throughout the interviews and translated to the memory-scape parents traversed in the interviews as they attempted to pull out details and recall chronologies; at some points in the interview the exact timing or specifics of events would go missing, while at other times participants were able to recall things with incredible detail despite the passage of at least two to four years. One mother admitted: "I remember what I ate before he passed. It's just very odd. I guess it just resonates in you and will never go away." Another father chuckled gently as his wife listed an intricately detailed series of dates and events related to their daughter's birth, death, funeral, saying: "She even knows what time if you ask her"; she replied, "Well… your mind is very sharp at that moment and you are just recalling it from… I don't know what shelf in the brain, but you just have it there."

i) "Oh my God, she was born, she is here"…"Oh my God, she's gone.""

In separating out the various scenarios amongst my participants, it appeared as though the shock associated with a pre-term labour had slightly different dimensions than that associated with being told there were medical complications before or immediately after an almost full-term birth. Parents who went into an early labour without any warning

were adjusting to both the unexpected end to their pregnancy and the unexpected beginning of their time as parents to a newborn baby. One couple used the word "perfect" to describe their pregnancy up until the seventh month (32 weeks) when early labour commenced. The mother remembers the pregnancy as an easy one, saying "I was not even once sick"; she mentions this in part to contrast the reality that after giving birth she contracted an infection in hospital and became incredibly ill, resulting in her having to stay behind for care when her daughter was transferred to the NICU. This mother also describes their tiny pre-term daughter as "perfect," which made the second shock of her death only a few days after birth even more profound. Although their daughter contracted an infection they had been told is a common cause of neonatal death, the reality of the unexpected birth coupled with the sudden death deepened the sense of shock. There was an impact to this coming-going that completely disoriented this couple. The mother describes the sensation as being "like a slap in the face" because they "didn't have time to adjust": "It takes time to realize that 'Oh my God, she was born, she is here"' and then 'Oh my God, she's gone.'"

Another mother conveyed a similar sense of shock, explaining her alarmingly early and unexpected labour at 24 weeks: "I didn't have any signs that she was coming or contractions or anything like that, so it was a big shock." The notion of "signs" touches on the idea that pregnancy is very much a hermeneutic embodiment; mothers are constantly interpreting their physiological processes and events to determine the stage of pregnancy and if it is progressing as their physicians have told them it should. It is interesting to note that all of this interpretation is carefully charted onto the

chronology that is a 'normal' pregnancy in medicalized terms. The "shock" of pre-term birth is the shock of having an expected chronology suddenly disrupted, putting the parents on a very different path than they had expected to take. The language of "expectation" also appeared throughout many of the interviews, hinting at this anticipation as part of the perinatal experience. From a communications perspective, it is interesting to note how certain technologies materialize anticipation by translating the body into information or, essentially, mediating embodied experience into a biomedical message. We see this in the ultrasound bouncing high-frequency sound waves off of internal organs to produce an image, or measuring levels in maternal blood for genetic conditions or birth defects, or reading amniotic fluid for chromosomal disorders. While the information gleaned from these media can sometimes change expectations, in other cases they can reinforce expectations that everything is okay in the pregnancy without acknowledging the unknown and the in-between that escapes biomedical data. For instance, at the time of interview the couple above who delivered at 32 weeks was still struggling with the fact that two and a half years after their daughter's death they still did not know why she was born prematurely, leaving her susceptible to a deadly infection. The father recalls the pre-term birth, saying "All the genetic tests were going fine. It came really as a shock. One day the pregnancy was changed." When we pull apart this statement, we see that the "change" was not in the pregnancy so much as in their expectation of the pregnancy going to term, based on feedback from the genetic testing. Other mothers expressed that they had read ultrasound results as assurance that everything was okay in the pregnancy, leaving them even more confounded when

something went wrong. One participant touched on this, explaining:

> I really did not have pains or anything… I wasn't feeling a lot of movement, so I went in for my ultrasound and found out that the baby hadn't been growing for about 6 weeks… It was just a big shock. 'What happened? I was totally fine for 32 weeks and immediately you are telling me…'

What is interesting in the last point above is that while this mother associated the ultrasound with her knowing that something was wrong, in reality the ultrasound was confirming or translating her own awareness of lessened fetal movement into a result that would call forward medical intervention. The sensation of lessened or no movement in the womb was something that at least two other mothers mentioned as well. One mother reported an interaction with her doctor on this point: "I had gone to him and said 'I just don't feel like this kid is moving as much as my first kid. I feel like something is up.' And he was amazing. He took everything very seriously. We did all these ultrasounds. And they were like 'Look, he's perfect!'…Physically he was perfect, neurologically not, not at all." It was not until after this mother delivered at 36 weeks that the extent of her son's medical condition became apparent when he began having daily seizures. It was not until 21 days into her newborn's 33 days of life that this family received a diagnosis of a neurological disease that could not have been picked up on ultrasound. Another mother whose son also had a neurological condition had likewise been concerned about the lack of movement in the womb, though in her case she felt the knowledge she read from her pregnant body before her labour and birth mitigated the shock after. About seeing her son hooked up to such extensive medical

equipment, she claimed: “I wasn’t shocked when I saw him because I guess I always had a feeling that something wasn’t right with him.” We can contrast this with her husband’s experience of one of the first times their son almost didn’t make it through the night, as he says: “no one knew that he was going to be very sick. It was quite the shock to everyone.”

Even when the mothers acted on their knowledge that something was “wrong” in the pregnancy, testing and ultrasounds were not always able to translate their meaningful sensations. The point I raise is not that the physicians were at fault for their inability to provide specific diagnoses (such a claim would be far outside of my research), but rather that prioritizing objective scientific optics or genetic patterns over the individual’s embodied experience is less a clinical misunderstanding than an epistemological foundation of medicalized pregnancy. As Barbara Duden (1994) has pointed out, the mother’s perception of fetal movement in the womb has been a site of contestation as scientific testing slowly usurped maternal ‘knowledge.’ Historical literature on birthing indicates the idea of “quickening”—the mother’s perception of movement in the womb—was well established amongst women and their female birth attendants as the way in which a child “announced its presence to the mother”; in the nineteenth century it was dropped from English usage as “pregnancy has become operationally verifiable” (Duden, 1994, pp. 80-81).

ii) “Everything happened so fast”

Going into unexpected labour or encountering serious health problems unexpectedly at

full-term clearly set a certain chaotic tone for the parents' birthing experience. Looking through the interview data, there appeared to be a discernible temporal quality to this chaos that one could describe in terms of a speeding up of the normal pace of daily life. Many parents used terms like "rushed," "quickly" or "fast" when explaining this time around their labour and birth or NICU entry. One mother said there were points when she was not sure if she "was coming or going," indicating a sense of disorientation in this quickened tempo. Another mother described the time around her labour as "chaotic," with a sudden birth followed by her daughter's urgent transfer from the birthing facility to the NICU, in which "everything happened really fast… we rushed over." In terms of the photography, a few of the parents also mentioned that one of the outcomes of this chaos was that the family was not able to think about making sure they had their camera with them when going into the hospital. One mother explains: "Because I didn't even expect to go into labour, it was basically a rush to the hospital, so I didn't bring anything and we didn't obviously bring our camera, but my husband was able to take a picture of him on my cell phone. So I have two pictures of him on my cell phone. That was all that we were able to take at the time." Another participant echoes this experience, saying "we didn't even think of bringing our camera because we were in such a chaotic state that that was the last thing."

It is important to point out why not having a camera is an exceptional point for parents who enter into critical care with their newborn, in contrast to those who experience a healthy birth in an obstetrics ward and are subsequently released home within a few days. Upon birth, babies who are experiencing complications are often

separated from their mothers in order to undergo further testing or monitoring. From there, in the case of all of my participants, some newborns are transferred to a higher level NICU if more extensive testing, monitoring or intervention is required. If the mother has delivered by c-section she cannot be released from the birthing facility for 48 hours, meaning if the newborn requires immediate transfer to another NICU, the mother must still stay behind. The camera, then, mediates the space between the mother and her newborn in the first few hours or days of life by providing the mother with a picture of the newborn who has been moved often miles away. As my participants explained above, not having a camera in those first few moments can mean the mother does not see the baby until she is released and able to join at the NICU. The mother who was rushed into early labour without a camera had her "favourite" photo of her daughter taken by the obstetric nurses (with the unit's camera) in her birthing facility right after birth. The mother explained that she was not able to get out of bed to see her daughter after the c-section, so a nurse took the photo and printed it for her to keep in her room. Although this participant was not able to recall the details of how the nurses at my research site initially offered to take photos, the taking of this first photo was particularly significant for her: "I remember initially at [the first hospital] when they offered to take pictures and that they had the camera… I was thrilled because I didn't have a camera and I wanted pictures of her. So this first picture was very meaningful for me."

iii) “We had grief mitigated by expectation”

Two of my participants had quite different experiences in terms of expectations, in that they had been made aware of their baby’s potential health complications in the first trimester of pregnancy. In both of the cases (one mother and one father from two different families), the pregnancies were carrying twins, with one baby progressing “normally” and one developing at a slower rate and/or exhibiting signs of other health problems. These parents were also both told by their physicians that any kind of prognosis would depend on the pregnancy going to full-term and what the doctors might discover after birth. While both the mother and the father mentioned their “hope” for two healthy children, they also both used the term “no guarantees” when recalling how their doctors had prepared them for a negative outcome. In both cases the babies were delivered pre-term and rushed to the NICU while their twins remained in a lower level NICU for monitoring but minimal intervention. Both of these parents also had older children, meaning the families traveled between the NICU, the second hospital and their homes on an exhausting schedule.

This father described the news of potential health problems as “a tremendous shock,” and then his wife’s pre-term labour as “the first of many great surprises.” Again this points to an immersion in and duration of the shock rather than an acute charge; however, the father went on to clarify his feeling of shock in a way that also suggested receiving this knowledge early in the pregnancy was helpful for him to accept and cope with what was lying ahead for his family across the 29 days of his son’s life. He felt thankfulness for having the doctor tell them the “candid, helpful truth” that it was not

likely they would have two healthy children. Even if it was a jarring revelation, he goes on to say "it was probably the best thing for us." This same father told a story of his friend whose young child had died instantly in an car accident, and compared this to his own experience of knowing his son might not survive through the pregnancy: "We had grief mitigated by expectation. He had grief amplified by shock. The fact that we were able to understand before [our son] was even born that getting through the delivery, getting through the first week, getting through the first month, that none of these were sure bets, particularly the delivery… having that expectation I think was helpful." In retelling this part of his story, he also mentioned that his wife had held on to the hope that their sons would survive and that he felt this hope also shaped her own experience of their time in the NICU and her ongoing grief. Originally it had been his wife who contacted me about the research, but she let me know about a week before the interview was scheduled that she was not up for the conversation and her husband would be coming instead. The father surmised in his interview that her hope for their son's survival might have made intensified the impact of loss for his wife. He continued:

> Subjectively, as a loving mother who gives of herself to her kids the most magnificent way possible, she always took the belief that he was going to live… I think the rational part of me, hearing what the doctors were saying over and over and again… again, bear in mind that I was typically the one speaking to doctors. Vainly, I would try to strip away the emotion and listen very carefully to what they were saying and what they were typically saying to me was that the expectation here doesn't match up to what my wife was clinging to. Essentially

> we were walking hand in hand together down almost two divergent paths, where she was living with the hope and the expectation that he was going to make it, whereas I was living with the realization that chances are better than not he's not.

By contrast to this family's experience, the mother participant I spoke to who had been aware of her twin's health issues early on was one of the only participants who did not use the term "shock" at any point in our conversation. In the end, the fact that she delivered early meant she and her husband "kind of knew… that we wouldn't have a good result in the end." There was no solid prediction, however, as she goes on to qualify: "But he was strong. They didn't even think he would live past birth, but he did live nine days." It might also be worth noting that this mother's older daughter had also been in the same NICU for almost a month as a baby for a major surgery a few years earlier. There was at least some familiarity with this space and even the feeling of having a child in critical care. It is further possible this familiarity mitigated the overwhelming nature of the hospital environment, though there was certainly no indication that it lessened the gravity or grief around her son's death.

In the end neither of these parents took many photos throughout their time in the NICU, up until the very end of their newborn's life. Once their sons were taken out of their isolettes and had life support removed, the mother had nurses take photos and the father had a professional photographer come in to capture their family's last few moments with their newborn. What was especially remarkable in terms of similarities in these photos that were specifically around the deaths of their babies, was that neither of

these participants had looked at their EOL photos since having them taken years earlier. Both of them had a very complicated relationship to the photos, being "grateful" and "thankful" that they exist, but not being able to think of them as anything but horribly painful images of the suffering their children were going through. I will talk more about this in Chapter 6, but for now want to gesture towards the possibility that the preparation or anticipation these two parents had in regards to the possibility that their children might not survive relates to their sense of the child's time in the NICU as one of illness and dying from the outset; in some ways they were not given the opportunity to think hopefully of their time in the NICU as a temporary state that would pass into a 'normal' childhood and life beyond the hospital. In contrast, for other parents whose baby's chance of survival was completely unknown, the overturned expectation of a healthy pregnancy and birth led into another expectation of recovery. These expectations carried with them a sense of a present and a future that framed the parents' experience in the NICU as duration, or as a "journey" as one father called it. This language gives the sense of a beginning, middle and end that parents were travelling along. What I illustrate below is that the way in which parents imagined this journey's end created a certain temporal dynamic within which parents negotiated photography as something that either needed to happen right away or that could wait for a "happier" future, depending on how much time they imagined they would have with their newborn.

5.2 Not Now/Here, But Then: Photography and Expectations of Recovery

As I touched on in my literature review, much of the existing clinical research on EOL photography was carried out as research into parent satisfaction with various hospital bereavement protocols. Determining that a high number of surveyed/interviewed parents were happy they had EOL photos taken, however, does nothing to explain how these parents experienced this photography or came to desire these photos. My intention in focusing on parent experience more broadly in my interview questions was to allow for an exploration of their process in making sense of this photography as part of their time in the NICU, in addition to their experience with the photos after the hospital. Analysis of this experience requires separating the photos themselves from the act of photography in the context of the NICU. Here I assumed a certain significance to the fact that the NICU is a clinical setting based on how rare it is for personal photography to enter such spaces of medicine, illness and death. While cameras are pervasive in social and intimate spaces today, North American culture is still a bit squeamish when it comes to documenting or sharing images of our bodies as they deteriorate or fail altogether. So how do parents come to embrace personal photography as part of their "journey" through critical care? Moving away from the representations produced by this photography or how they were shared afterwards, here I want to stay focused on how parents came to accept the camera as an extension towards their sick, dying, or recently deceased newborn. My findings show that this acceptance was not always smooth or immediate. They further reveal that the move to this acceptance through a path of hesitation often related to a certain perception of time. While some parents were taking

photos right from the outset and continued through the death of their newborn, others held off on photography thinking they could defer the picture-taking to a later time in happier moments outside of the NICU. Their decision to start taking pictures or consent to having nurses take them seemed to shift when they gained an awareness of having a finite amount of time with their newborn, which the camera was then called upon to capture.

i) "they actually sat us down and told us that she was going to die. And then she didn't die"

One of the characteristics of critical care is a rapid pace of information translated into knowledge then applied to the maintenance, intensification or withdrawal of technoscientific intervention. This translation and application can transform perception of the patient as a body that is living to a body that is dying. Even the suspension of waiting for such information to be gathered has a certain hum to it that is never quite static. The line between living and dying, stability and deterioration is uniquely thin in the case of neonatal intensive care due to the tiny systems that are undergoing the medical treatment. A few of the parents brought this point to light, referencing the rapid changes they noticed in their own newborn's body over their time from birth to death. For many of the parents who had weeks or months in the NICU, their initial shock was continually charged by surges of new information, new hope, new devastation, new potential, new endings. One mother's story captures this reality in the most poignant way, as she and her husband moved from hope to loss repeatedly over the five months

their daughter was alive. When her daughter was born prematurely she was transferred to the NICU for assessment, but fell ill along the way prompting the medical staff to tell the parents their daughter was going to die. The family stayed overnight in the NICU and "said goodbye," but their daughter made it through the night and went on to live for another four months. In telling this story, she declared: "It was a roller-coaster." This phrasing gives the feeling of embodied language, transmitting the sensation of speeding along an inherently turbulent but controlled track that feels simultaneously predetermined and unpredictable as it moves the body up and down, forward and backwards. She goes on to recount further confusion when her daughter was closer to dying: "And then again, when we thought she was going to die and she came home… we thought she'd die in 24 hours and she stuck around for 4 days." Again, the idea of the "roller-coaster" helps us grasp the up and down sensation and temporal sway of an unknown future hitched to an unknown prognosis. Over the months that her daughter was alive, hundreds of photos were taken by the family, the nurses and by a professional photographer at their home once she had been transferred there to have life support removed and to live out her last few moments with the family outside of the hospital. Yet, this participant alluded to the fact that photography became more of a focus for her family once their situation changed from being a family with a pre-mature newborn to being a family with a very ill baby who might not survive.

A few participants touched on this idea of having a sharper focus on photography towards the end of their newborn's life, particularly when the baby lived for at least a few weeks or a few months and the health outcomes were not immediately obvious.

Part of this focus can be explained by the fact that when the parents and medical team decide to withdraw life support there is a transition into end-of-life (EOL) care, which involves an intensification of bereavement support. While the nursing and social work team might be offering parents memento-making and counselling throughout their stay in the NICU, preparing for the death of the baby means this is the last chance for parents to take photos. One mother picked up on the nursing staff's focus in these moments, saying: "I remember later on when we knew that she was going to die, I remember people offering to take pictures. That kind of happened more so after we knew she was going to die." With EOL, there is a short amount of time to make decisions and yet a number of steps have to come into place before the photos are taken. For one, it is hospital policy to have parents sign informed consent forms before nurses or photographers take any photos on their behalf. As the Coordinator details the process:

> When we know that we're planning for end of life, it's that getting consent for being able do it as early as possible, grab the camera, have it in the room… most of the time death is not within minutes of that discussion, unless the child is actively dying, and that's a very different scenario and that means everybody's got to whip it together, but you usually have at least 24 to 48 hours where you can work through it with a family and decide what's important to them.

The Coordinator also mentioned that it is not only the nurses but the whole medical team who is dedicated to getting the photos for families. An example she gave was having the Respiratory Therapist suggest pictures while the breathing tube is removed

because that is often one of the only times the families are able to see the baby's full face without the equipment. She describes a hectic but conscientious scene:

> Sometimes it's as crazy as having three people around the bedside removing a breathing tube and taking out all the wires and tubes and a nurse or myself, who's another nurse, standing and trying to capture it all because we don't know how long that child will live after that tube comes out. And if the child is critically ill your best pictures are going be right after the tube comes out while they are still pink, because we know the colour change can be dramatic, so it's about capturing it early and then stepping back and saying 'okay, so what else can we do, what other types of pictures are important to the family.'

What we see in these two passages is the fast pace of events that might lend to the disorientation parents expressed as part of their experience. No matter the duration of the family's stay in the NICU, their is a quickness to the death and post-mortem transformation of a newborn upon removal of life sustaining equipment that in many ways explains the logic of having a camera in this space around these events; photography's quick capture can effectively intervene.

Before this final tempo is set in motion by decisions to withdraw life support, parents were not always thinking in terms of running out of time. Instead, I picked up on a theme of anticipating *more* time with their newborn that related to their hesitation to take NICU photos. Until a final diagnosis or prognosis was confirmed, some parents imagined a future with their child within which there would be opportunities to capture other moments that told happier stories from the child's life. In some ways these parents

were suspending the NICU time within the hope and anticipation for another time that was not *now* and not *here*. We see this in one mother's recounting of her resistance to taking photos of her son when he was first born:

> I was like 'I don't want to remember this. This is brutal. This is the first day. He'll be fine tomorrow. Lots of children are born and they have seizures in the first few days and they're fine.' I know people who had children like that. [My friend] said 'I still think we are going to take some pictures.' I was like 'Nooo. It's going to be fine and we'll have all these other amazing pictures.' So he started taking pictures. I relented because I was hopped up on enough painkillers anyway. But he took pictures and he was with us through the whole process. He took lots of pictures and then I started taking pictures and I took some videos and everything. Four years later, some of the pictures that he took are my favorites…Thank God! He wasn't rude about it, he wasn't like 'I don't care what you say.' He was like 'I think this is something that you are going to do. You took pictures of your daughter on the first day. This is part of his story.'

At one point this mother went on to say: "Once my friend said 'You're going to want this' and once I realized that after a day he wasn't getting better and he wasn't waking up, we started taking pictures. We still had no idea for anything. I think we were in so much shock." She touches on something important here, which is that her state of shock impacted her ability to think through these moments as part of her son's story and, even further, part of the story she would want to document. I want to look at this further within a few more examples, reflecting on other aspects of the NICU experience

surrounding these hesitations.

ii) “The last thing on my mind”

In telling the story of their newborn’s life and death in the NICU, participants described waves of information, processes and tasks that made up their experience as both parents (emotionally attached care-givers) and guardians (legal decision-makers for these newborn patients). Putting together a montage of the moments they shared across the interviews, I gathered that the “chaos” they described in the NICU spins out of the daily whirlwind of arranging travel to and from the hospital every day; arranging a place to stay if they are from out of town; consulting with a team of medical professionals; sifting through constant stream of highly specialized information; managing reams of clinical and legal paperwork; thinking through consent for bioethically complex actions that directly impact their child; letting family and friends know what is going on as things change; eventually making funeral or memorial arrangements; and, for five of my ten participants, caring for their other children throughout the whole ordeal. As we see here, the NICU is a somewhat disorienting space that calls on parents to quickly process and act on information in addition to their other work of simply being present to their child, parenting from the uncomfortable distance structured by the incubator technology that helps keep these babies alive. With all of this happening around and through the parents, the ability to process the meaning of having photos taken was often difficult to grasp. One mother captured this succinctly when I asked her about her thoughts on the photography at the time: “I think there was just so much going on that I

wasn't thinking about what to expect or not expect. I wasn't expecting to give birth to her when I did so everything was just a big surprise."

Part of anticipating recovery is imagining a time in the future when things are moving at a more manageable pace after the urgency of intensive care has passed. This future presents itself as the more suitable and amenable time for taking pictures. This played out for one couple who were not taking many photos in the first few days of their daughter's life, in which she was pre-term but otherwise healthy and expected to recover. The father mentioned not having a camera nearby for one of the few "precious moments" they were able to hold their daughter when she was out of her incubator. In the interview the father lamented not having those photos but explained his position in the moment: "you are not thinking that something will happen… You see that everything is good so you go 'Oh, I have time to make some pictures.'" He suggested that photography "doesn't look relevant at that moment," but remembers the nurses bringing it to their attention: "There were two nurses and they were suggesting [to take pictures] actually, because at the time you don't think about it… I think at that time, I couldn't even think about that. You are somewhere else." His wife agrees, offering her perspective on why she was less focused on the photography at the time: "For me, at that moment, the picture is the last thing you think of. Even the nurses coming in and out, it was like… this is our private moment." Reflecting on how she felt about the photos at the point of the interview two years later, however, she expresses gratitude: "Now, I'm very thankful for these pictures actually…They were the ones with the sense. Nurses at the hospital were the ones that were suggesting "Do you want to take

the pictures? Do you want to take the prints?"" What became clear through many of the responses is that although photography is the "last thing" on the parents' minds, as a few participants termed it, the nurses played a significant role in bringing the photography into relief as something parents should consider.

Returning to the father's language of being "somewhere else," we see the nurses bringing the couple's attention to the *here* and the *now* that was quickly passing. This presence is complicated, however, as the responses of this couple and other participants also indicate that the parents were not simply lacking lived attention in these moments but rather focused on just *being with* their children. In this way the photography appears as an unwelcome mediation to this *being with*. As the mother above says at a later point in the interview, her first response to having the nurses offer to take photos or do any other legacy work with them (such as plaster casts of the baby's hands and feet) was to say "no, no, no, leave me alone. This is my moment." One thing to note is that this couple's daughter only lived for a few short days and her death was quite sudden. The only time they had to hold and spend time with their daughter outside of her incubator was after she had died, so the nurses were rushing around to get mementos and photos in a short amount of time that overlapped with the parents simply wanting to have a moment with their daughter even though she was already dead. This heightened the sense of intrusion associated with the nurses coming in and out and offering photos. In other words, the couple was not against the idea of having photos taken so much as having their time interrupted. In the end they did have nurses take a few photos of them with their daughter as a family, but they also took more photos just between themselves

as the nurses allowed them to stay with their daughter's body for a few hours to say goodbye.

For another mother who also only had a few days with her son, the idea of taking photos around his death was much less comfortable. Her husband had taken a few pictures of their son on their cellphone right after the birth, but the family had not taken any others over the rest of the time in the NICU. In part, the lack of picture-taking stemmed from the mother's fear of "disturbing" her son, who had to be kept in his incubator at all times. Things changed for this mother when the decision was made to withdraw any life-sustaining technology, which would mean the parents could hold their son for one of the first times as he died. She remembered the nurses offering to take photos for the family once her son was out of his incubator, and her initial reaction was incredulous: "What are you taking about?!" I don't know if it is just the whole idea of death. For me, I would never think… I didn't even know that they took pictures of funerals. To me, that's very morbid." As she continued to reflect on the photography, however, it became clear that her initial reaction was not an absolute no, but rather a negotiation of her feelings on the photography in the moment and her imagining of what she might want in the future. We see this in her explanation of how she came around to having some photos taken with her son in his last few moments:

> At first I was kind of 'Do I really want pictures of this?' and then I spoke to the nurses and they kind of said to me 'You might think this way now, but in a couple of years from now, you might want them.' and then I thought 'You know what, right now I'm going through a lot of emotion.' That was the last thing on

> my mind… to have a picture taken of him in our arms. That's not what you're thinking, but it did make sense to me.

It is worth reflecting on this response in relation to the scenario with the couple above, where I proposed that the nurses were bringing the couple's attention to the *here* and the *now*. I build on this point to suggest the nurses are balancing the parents' experience in the NICU *now* with their experience in the future as bereaved parents who might value photos of their deceased newborn. So, it appears nurses are also prompting parents to think beyond the NICU, to a time that is not *then* and in a place that is not *there*. Therefore, I argue that the parents I spoke to experience the EOL photography within a complex tension of temporalities that they navigate and from which they take meaning.

iii) "The one regret I have is that for the first two months I hardly took any pictures"

Based on these findings, it initially appears as though the photography might not be worth the intrusion or the addition of yet another decision for parents to make in such an overwhelming process. However, each and every one of my participants—even the two parents who never looked at their photos—made clear the value they placed on the pictures and their deep gratitude for having them taken. The parents who first hesitated to have photos taken were no less grateful of their pictures than the parents who had been on board from the outset. For example, the mother whose friend took days to convince her to take photos eventually declared: "Thank God he took the pictures because it's so important." She in fact went on to do substantial fundraising for other hospitals that do not have any kind of photography because she felt so strongly about

the role the photography and other memento-making could play in helping families heal and move forward. In her words, "…at the end of the day once they are dead, and not saying that lightly, you don't have anything except for photos… because you'll never have anything again." She also believes photography should be a part of all paediatric care, even in cases where the child survives:

> if the child lives, and obviously we hope that they all do, the child could turn around and be like 'Oh my God, look how little my little foot was, look at how cute, look at how many tubes I had, and now look at me I'm 27 years old and healthy', that kind of thing. It gives people hope…It's important that those kids have their pictures taken too, and it gives other people hope. And then for the people who obviously aren't going to have hope they have pictures as well.

Her phrasing here makes a striking move that suggests the photos come to replace the "hope" parents hold on to.

The mother who initially thought of taking pictures around the death of her newborn as "morbid" also came to feel strongly about the benefits of photography, offering advice to parents who might experience a neonatal loss in the future:

> I think if I had to counsel someone going through it, I would say definitely take advantage of all the mementos that you can keep. Even though at the time you are probably like 'no, I don't want this. I don't' want that,' but I think any little thing… I have a little paper copy of his footprints on like a card that they had made for mother's day… but I remember the nurses mentioning 'we can get you an actual clay [mould]' and I said not to that. I regret that now. I think any little

> thing you can grab as a memory is important. What people do with those little memories is a personal thing… You have to grab it all and then when you are at a point where you are okay with looking at them or touching them or displaying those pictures… that's individual.

Something this response calls forward is the idea of "regret" for not taking certain photos or mementos that are offered. This resonates with another father's experience, who offered this:

> The one regret I have is that for the first two months I hardly took any pictures. You lose that. I can't remember that… I see certain pictures and then eventually it comes back to me, like 'Oh, this is what happened'… but for the first two months, it's like I have nothing… I had never taken photographs really up until that point. I just wasn't thinking, or I don't know.

Tying this response back into the themes of temporality and expectation, it is striking that this father started taking photos not when his daughter was close to dying, but when he thought his daughter was going to survive:

> At one point things were looking good and it was like the best-case scenario and we thought she was going to make it, so I just wanted to document. I had this vision that she would be a teenager and I would be sitting with her and looking at them… Now I look at them by myself. I'm glad I took those pictures. I'm really glad. It's a blessing.

Although in many cases the anticipation of recovery made parents feel as though there was more time in the future for photos, here we see that expected recovery can also play

into parents' wanting to take more photos to document their child's story, or ultimate "triumph" as this father put it:

> I started taking pictures because I was creating this collection of what would be her triumph and I would show it to her when she grew up, but then half way or three quarters of the way through it, I started to realize that this might not be a collection of pictures that I would show her when she grew up, but more of a memorial of her brief life.

There is no one way parents respond to the idea of taking pictures in the NICU, but there are discernible patterns across the ways in which they make sense of photography in that space. The interrelated spatio-temporalities I have touched on so far—the shock of chronological disruption, the anticipation of a recovered future, the quickened tempo of critical care—go a long way to illustrate the rich fabric of lived space-time parents experience and within which the photography appears and retreats, and through which it cuts. The repeated language of "last thing" on one's mind implies that there is a series of things that parents do think through and act on, prioritizing as they move through the critical care. Assembling this list of priorities is a task made arduous by shock, fear, and an overload of highly specialized information. It is also made challenging by the overwhelming tempo of intensive care, which is not banal but made strange and urgent by rapidly changing conditions, unpredictable outcomes and the demand for fast yet momentous decision-making. The feeling of not knowing what will happen next bolsters the logic of intervention to sway the outcomes; without intervention, the future is not safe. Critical care is a categorically continuous, extensive, and potentially

invasive form of medicine designed to work against severe and life-threatening conditions. It assumes that the only difference between "life-threatening" and "cause of death" is a guard held steady by science, medicine and technology. This guard has extra work to do in the case of neonatal critical care due to the vulnerability of tiny bodies. Without the technoscientific mandate of the NICU, there is no future beyond these moments of crisis and anticipation of recovery disappears altogether. Forward-looking hope that is created by the unknown is a contemporary temporal state. Crisis, control, hope, and grief are formed through the NICU as a biomedical space.

The NICU is not a neutral container for shock and urgency described above, but rather promotes a spatio-temporal configuration of crisis in which bodies and technology come together with explicit intent to shape or control a future. As shown in the previous chapter, this NICU itself comes out of a self-sustaining logic of intervention that medicalized pregnancy and imbricated neonatal health and death with technoscientific intervention. Parenting a newborn in this context of critical care requires a delicate balance of endurance, presence, distance, acceptance, and resolve. Making sense of the photography is one of many processes of negotiation through which parents have to make their way, which lends to the complexity of their experience of and response to the prospect of having photos taken. For all of my participants, however, the decision to have at least some photos taken (either by nurses, by a volunteer professional photographer, or by the family) was eventually made.

I turn now to reflect on the participants' experiences with having photos taken And taking photos themselves, with an eye on the characteristics of the NICU that have

been described both above and in the previous chapter. I want to expand on the point I introduced in the last chapter regarding contemporary EOL photography facilitating different kinds of photos, which one father distinguished as photos of the baby "living" versus photos of the baby "leaving." My findings indicate that, perhaps paradoxically, the medical equipment that was responsible for keeping the babies alive also signified the babies' illness and potential death. The equipment also distanced parents from their babies in ways that seemed to subjectivize the babies as critically ill neonatal subjects rather than as living newborns who had families wanting to keep them close. I conclude that the photos taken of the parents holding and interacting with their newborn were not valued solely for their "validation" of the baby's existence. They were also validation of the parents *as* parents in a narrativized identity and an embodied position of proximity to the newborn life, parents whose attachments were sometimes dismissed in the interest of sustaining life in biomedical terms; in the two sections below I consider the ways in which EOL photography materialized relations that far exceed these terms.

5.3 Parenting: Photography as/and Interaction

i) "without the tubes and the wire and this and that"

The prominence of medical technology in the NICU emerged throughout the interviews as a crucial part of the parents' experience of the photography in two main ways. For one, as touched on in the previous chapter, the newborns had to live in incubators for most of the time in the hospital and were therefore not often held or moved around by the parents until the decision to withdrawal of life support was made. Second, the

newborns were also often hooked up to equipment that it typical of neonatal intensive care (i.e., ventilators, drainage tubes, intravenous pumps, or sensors), therefore it was rare to catch a glimpse of the baby's face or body without the interference of technology. Words like "tubes," "wires" and "equipment" were mentioned many times throughout all of the interviews and almost always in context to taking or sharing photos. Almost all of the parents talked about how important it was to them to have at least some photos of their son or daughter without "all of the technology" in the picture. I noted that many of the "favourite" photos parents pointed out in their albums were of the child out of the incubator and without equipment around. One mother did not bring her hard copies of the photos to the interview (because we spoke in a private room at her workplace and she did not want to bring the album to her office) but kept the photos on her cellphone, so had them available there. These were photos that were taken of her family by a volunteer professional that the hospital had arranged. As she thumbed through them she pointed out images of her son without any medical equipment around him, as well as a series of her older daughter on her own:

> When [he] was born and then when he was in the NICU, they gave him a little bit of oxygen… so we had him obviously on oxygen and at one point he was intubated for about 1 week… One of the greatest things about the pictures is that… I'll show you one. That's my favorite picture… it's that we took off everything and we just had an oxygen cart next to us. So a lot of the points where [big sister] is having her picture taken a lot, it's because we are giving him oxygen. But for us, it was really important that we had some pictures

without the tubes and the wire and this and that.

The fact that the couple removed breathing equipment and administered oxygen in between portrait sittings gives a clear sense of the weight technology-free photos held for them. This was the same mother who had fund-raised for another hospital to provide resources for photography in their NICU, thinking of how important it was even for families whose baby might survive and look back on their NICU photos saying "'Look how little my little foot was. Look how cute. Look at how many tubes I had. Now look at me, I'm twenty something years old and healthy, etc." Even in this scenario she imagines the tubes to be a central part of the child's story. The point, then, was not to entirely edit out these medical challenges as part of her child's life experiences, but to *also* include moments of their son simply being or looking like their son, as opposed to a critically ill newborn; the lines between 'being' and 'looking like' here are philosophically substantial and will be addressed in the final chapter.

The theme of medical technology in terms of the photography also arose in my interview with the Coordinator, as she explained how it is a team effort amongst the staff to get families thinking about the photography and how often this revolves around the removal of equipment:

> I may be the one to have the first conversation if I'm here… or the Social Worker might, or the bed-side nurse or maybe even a Respiratory Therapist who may have a relationship with the family and says, 'We are going to be taking that breathing tube out of your baby and you are going to see their face for the first time. You might want to have a camera right here so that you can capture when your baby

looks the best.' Really the whole team is conscientious and cognizant of the value that this might have for families and encourages families to be part of it.

A few of the parents echoed the idea that their "best" or "favourite" photos were taken of their newborn immediately after birth or immediately after the withdrawal of life support. Parents often valued these photos because of the baby's "healthy" or "normal" appearance, which was more likely when the baby was first born and/or before too much time had passed after vital signs started to shut down. For instance, one mother reflected on how she differently she felt about the photos her husband was able to snap of their son on her cellphone immediately after he was delivered versus the photos taken later on as his condition deteriorated. She felt much more comfortable with the former: "The picture on my cell phone is such a different picture. He was just freshly born. He looked like a regular baby. He had the tubes, but he didn't look as ill." This mother had only looked at her EOL photos once between her son's death and the time of the interview, taking them out at the one-year anniversary of his death. At that time she found the photos very hard to look at, recalling that all she could see in them was how "sick" her son looked.

Within my analysis, the theme of having "favourite" photos related to the baby looking "healthy" or "normal" related to the theme of "living vs. leaving photos" that I have already mentioned. This title came out of one of the interviews with a father, who used this phrase to explain why certain photos held such different meaning for him than others. This father had also not looked at his EOL photos beyond the day they had arrived at their home, mailed from the photographer. When this father arrived at the

interview he mentioned that he had brought some family photos instead of the EOL photos, and laid seven of them out on the table. Most were of his family in what he described as "happy" times together, and two were from the time around his twin sons being born. One of these photos was of the father in another hospital, holding his surviving twin and his daughter who was a toddler at the time. The other was of his son who was in the NICU, lying in his incubator. The photo was taken by a family friend, just as his wife had put her hand in the incubator and their son grasped her finger. He elucidated: "I deliberately chose other photos to bring in to show you and share with you today in talking throughout the experience. I mean even here, there are seven photos and just the one of him… the one we are most comfortable having around the house" (this photo was in fact the only picture of his son they had displayed in their house). Throughout the interview he would return to these images in relation to the EOL photos that were not present, trying to work through for himself—as much as for me—why he experienced these photos in such contrasting ways. Eventually, he came to this response:

> I like this picture because it's a reminder of him living. The pictures from that day are a reminder of him leaving. As I've just been going through it in my head, that's what I just arrived at. This isn't something that I've been cognizant of until now, but talking it through here with you… I don't mind this picture because it is a precious moment of him living, him connecting with the mother that brought him into this world and cared about him more than anyone else, say except perhaps for myself. That's him living, that's not him leaving.

This father used the term "impact" to describe how the photos of his son "leaving" hit him and his wife "on a very personal, intimate level." This wording evoked the same sense of having the loss feel like a "slap in the face" as another mother had articulated about the shock of her daughter's unexpected birth and sudden death.

Another couple mentioned the same kind of distinction made between photos they had taken throughout their son's life in the NICU versus photos around his death. Over the two months they had with their son they were able to take many photos and have a lot of family members visit the hospital to meet their son. Their album only included one photo from the day their son died, although they had mentioned they took hundreds of photos over their son's life. The mother remembered that nurses offered to take casts and make other mementos on the day they decided to withdraw life support, but could not recall the nurses mentioning the option to have a professional photographer come in. The mother made sense of this in relation to how they were feeling at the time:

> I guess for us, because we had so much time with him, getting pictures of him in his final moments of when he had already passed away, wasn't how we wanted to remember him. Because we had two months of him doing amazing things, we didn't really need to see those memories as well. I think that's how we felt with that. I know with *Now I Lay Me Down to Sleep* sometimes they'll do stillbirths and things like that. If you don't have any pictures, you don't have those memories, you would want to get those pictures done. I think I would want them done in that kind of situation, but with him, I don't think we really needed them.

The father in this interview followed up regarding the lack of photos around his son's

death with language that was very similar to the other parents I reported in the first section of this chapter, saying, "I don't think it was really on our minds." The mother clarified from her perspective: "I would have loved to have some professional photos done of him, but I think in those last moments and in that state, it's too hard. Even seeing that picture for me is hard"; here she is referencing the one photo from their album from the last day with their son, which was of her husband holding the newborn and looking up to the camera, smiling faintly. Her difficulty with the photo was because "you could see it in his face too. It's just a sad picture," acknowledging that her husband is trying to "force a smile." It is valuable to note how the sadness of this photo was not something these parents wanted to hold on to, which in some ways contrasts the mother who felt one of the important functions of her photos was getting at the "physicality" of the moment, even if that physicality embodied the "devastation" they were experiencing at that the time. These divergences indicate that there was not universal interpretation of the photos or the photography amongst the participants, but rather a nuanced process of meaning-making.

ii) "you try to live a lifetime in four short days and try to do all these things"

In looking at why parents identified certain photos as their "favourites," having the child look "healthy" was not the only consideration. Another recurring theme in the preferred photos out of the sometimes hundreds that were snapped is that they were often candid action shots involving nurses and families, as opposed to a 'posed' portrait style of the newborn alone. By this I mean that the "favourite" photos most often

involved an interaction between the parents, nurses and the newborn. One mother mentioned her "favourite" photo, which was not in the album she brought to the interview because it was framed and displayed in her bedroom at home: "I actually don't have it in there, but he's having a bath and he's in like a blue bowl and he just looks like a normal, healthy boy. It's one of my favourites." The "normal" she emphasized here was not in singular reference to the way her son appeared in the photo, but more so to the activity of bathing one's newborn, which is typically one of the preciously banal moments that make up 'parenthood.' She went on to say there was a nurse in this same picture, which meant a lot to this couple because they had developed friendships with many staff members and wanted them present in the photos that told their son's story.

Many of the photos the participants had of their more extensive interactions with their newborns were taken right after life-sustaining technology was removed. Although embedding the photography in other emotionally and ethically force-full movements around end-of-life is not doubt a significant aspect in the parents' sense of having the photography be the "last thing on their mind," the withdrawal of treatment also meant the newborns were able to be moved out of their incubators. In fact many parents pointed out specific photos in their albums, verbally captioning the importance of the photos as exactly that: "That was… the first time she came out of the incubator." The removal of tubes, sensors and release from the incubator was especially meaningful because it was often the first chance parents had to really hold and interact with their newborn for more than a few minutes. These were often the only moments participants

had to perform the gestures of "parenting" without the medical technology crowding the scene or distancing them from their babies. This helps explain why nurses so often introduce or highlight photography purposefully at the point of withdrawing life support, which otherwise seems like a particularly sensitive time to position the camera between the nurses and the family (as it is often the nurses or other staff who take these photos while the parents are engaged in the "parenting" activities).

In offering to take pictures, the medical staff was concurrently introducing the idea that it was okay for parents to *be* parents by engaging and interacting with the baby directly. This is especially important for parents of critically ill newborns who are often afraid to hold their tiny babies after days or weeks of being told how dangerous their germs might be, how precarious the babies' systems are and how the baby might be in pain. With the incubator being both an obstacle to holding their baby but also understood as crucial to their baby's survival and comfort, at least three parents directly acknowledged their fear around holding their baby or causing their baby any discomfort. One mother admitted her and her husband were "really scared" to hold or move their son after so many days of only looking at his tiny body through the incubator, and required the nurses' encouragement to take this step. She recalled the nurses reassuring them, "Don't be scared. You are the parents. You are not going to hurt him." In the end she was delighted that the nurses helped them through their initial fears, ensuring the couple had the opportunity to feed, clothe, and hold their son. It also meant a lot to her that the nurses were focused on both facilitating these parenting interactions while always keeping the baby's comfort in mind:

> Initially we were not allowed to take him out of the incubator, but the last two days they did transfer the baby to our arms, covered him, moved all the equipment. That is something that they are really good at too at [this hospital]. Although there are literally so many wires and tubes and small things running here and there, they are really good at transferring without troubling the baby.

Another mother also shared her thoughts around not wanting to "disturb" the baby, which was so intense it held her back from taking photos through the incubator or even leaving the incubator uncovered:

> My whole thing was that I just didn't want to disturb him, I didn't want to upset him, I didn't want to make him more sick. The nurses were even like 'take off the blanket and look at him,' but to me that was like 'oh my god, let's see if this is causing him more pain.' I would stare at the blanket. That was my choice of course. In my head, I just thought 'oh my god, I don't want to cause him anymore grief.' I knew he knew I was there.

I want to pause on the language of "there," which came up in different ways throughout the interviews that we can connect through the idea of having the photos ground the parents in the "chaotic" NICU environment. Like this mother, other parents also mentioned positioning themselves in front of their baby's incubator for hours on end, as one mother notes here: "I think it was initially adjusting to the fact or having a mind set of 'Your baby is sick. He might not survive. He might not be well.' There is a lot of grieving and looking at him and just staring at him and just spending time in front of his incubator." This idea of "spending time in front of [the] incubator" was repeated in

other interviews as well, with one mother noting stages from "looking" to "holding" along the way: "Because initially he was literally just in the incubator and we would just look at him. Then we were allowed to touch him and then we were allowed to hold him." For one mother the problem with only being able to "look" at the incubator was that the incubator needed to be kept at a high temperature and was therefore often steamed, blocking the parents' view of their child—which came across in one of the photos the mother pointed out, since she still took a picture of the incubator despite the incubator appearing almost opaque due to the steam. The "thereness" of sitting in front of these incubators and "looking at" the incubator was clearly very meaningful for many of the participants. I want to contrast that to one father's phrasing around his initial reaction to the photography seeming irrelevant, in which he states: "I think at that time, I couldn't even think about that. You are somewhere else." Once the initial shock subsided and this father did start taking photos, he then sounded much more grounded in the NICU as the space he was sharing with his daughter, dressing and bathing her and taking many hours with his wife to say goodbye. As a technology, the camera was used to counter the distancing effect of the incubator and other medical equipment in order to bring the parents back from "somewhere else" to the NICU, to orient the parents towards their newborns in meaningful ways.

The more time parents had with their newborn, the more opportunity they had to feed, bath, clothe, hold, or read to their babies. However, even when the baby only lived for a few days or hours, the nurses would facilitate the opportunity for parents to carry out at least some of these important moments. A mother talked about the nurses'

helping her family live out and capture some of these moments even though her son only lived for one week:

> Initially he wasn't dressed, he was just in his diaper… when they knew that we were going to take off the life support, they said 'Let's dress him a little bit and let you hold him'… because he was always in the incubator. Initially we weren't allowed to go in there without masks and gowns, but then they said 'Okay, you know what… the germs are not going to really make any difference. He's deteriorating in other ways.'

The interview responses did suggest that the parents who had the chance to take a good number of these "parenting" photos experienced their pictures and albums more as "happy" family pictures than as bereavement photos exclusively. In asking one mother about the photos she chose for her scrapbook she replied:

> I guess I wanted something that tells the story a little bit. If you look at them, they are not just us holding him… it's feeding time… we are cleaning him up here a little bit and then we are with grandma and with our close friends, it's me reading to him. They are the things that we were able to do with him in just a couple of days.

In the quote above we again see the connection between the *living relationships* and the story-telling element of the photography. Another father picked up on the sense that the photography was connected to these meaningful activities, almost intertwining the acts of capture with the acts of parenting: "at this point we know she is going to die… I know that I just wanted as many pictures as possible to try to capture… you try to live a

lifetime in four short days and try to do all these things." Returning to the often overwhelming temporal pace of neonatal intensive care in which time is often something to fight against, the camera seemed to help parents move through these meaningful activities with their newborns with intention and presence on the *parenting* and on their newborn's living moments, rather than on the fact that their newborn was also dying.

This last point is not to suggest that all parents make the connection between the photography and these moments, or that they automatically think of these moments as "happy" ones. From the Coordinator's perspective, the acceptance of photography was often a process helmed by the nurses but very much up to the parents to navigate in the end:

> The issue of photography is one that many families wonder about and question. When it is initially brought up you get multiple responses, but usually the first response is 'Why would I want to remember this?' which is always leading to the parent kind of needing to remember that they are the parent of this child and they will always be that child's parent, and that pictures can help tell the story of their baby to those who may not be present to them, but also to help the parent remember the good experience. That might be the first cuddle, the baptism or the blessing, or it might be the first time that baby was held without tubes. For some of those families, those are very precious moments. We have other families who come into the unit with cameras in hand and are taking pictures right from the beginning and when we offer pictures around end of life, they buy

> in very quickly. Some of them need some discussion. They need to sort of know that if the pictures are provided, that they don't have to look at them, that they have the opportunity to do what they want.

Amongst my participants, their experience of the photography very much aligned with the nurses' intentions here even if the parents accepted the photography at different paces or to different degrees. Across the board, however, all participants articulated in some way that the photos and the photography were a crucial aspect in their *knowing* their sons and daughters in life, not just memorializing the death of their newborn after the NICU but telling the family's life-stories. Most of the participants distinguished between photographs and other mementos (such as blankets, clothing, hospital bracelets, plaster casts, etc.) for this reason, as the photographs communicated processes, rituals and interactions that together helped tell the story of their newborn's life, beyond simply providing "evidence" of their life as some research suggests is the role of such material objects (Layne, 2000). I understand this photographic communication as Merleau-Ponty understood Cézanne's painting: not as representation—not as symbolic text separate from experience—but as "bring[ing] the material world alive; it does not measure or represent reality but emulates the way it materializes in perception" (Coole, 2010, p. 105). For example, one mother who took many photos along her four-month NICU stay remembered her motivation to taking the photos: "At that time, I just thought 'This is part of her growing, part of the experience of her life.' I just wanted to document it along the way like I did with my son." We see here a folding of the photography with the experience of her daughter's life; there is an

intercorporeal chiasm, the photography bringing the mother and the daughter to life, as the mother and daughter (as photographic subjects) bring the photography to life. When asked about the difference between other mementos and the photographs, another mother said the distinction was in the way the photos "said so much." There is a sense in this phrasing that the photos themselves speak the story as narrative, not as spoken texts but as living speech, as a mode of situating. This is a key point to observe, as it shifts attention away from the moment of death to the process of living, the process of parenting, and the process of bringing this part of the parents' life forward with them. One father even felt the pictures were not sufficient for the narrative that he needed to share, so he put the images together within an intricately detailed slideshow with captions, transitions, and music: "The photographs are only part of it. The photographs give me the opportunity. Without those photographs, I can't have this, but photographs alone aren't enough. It is how I tell the story and how I communicate my loss, my pain, my love for my daughter. It is so funny… it is like eight minutes that took me like 15 hours to create, but it was a labour of love." The term "labour of love" is one often used to describe parenting itself, and arguably could also be used to describe the work one does in grief and mourning.

5.4 Nursing: Photography as/and Support

My study findings suggested nurses are often the key players in facilitating more extensive photography in the NICU, specifically through the facilitation and encouragement of parenting moments that bring the families together with their

newborns. This finding was validated through the work of Limbo and Kobler (2010) as well as the PLIDA Guidelines (2008), where health care professionals are encouraged to enable relationship-based care to support the family in their bereavement. My interviews made apparent how deeply aware parents are of the fact that the staff around them in the NICU are not only present in a clinical capacity, but also in an emotional one. One mother acknowledged this emotional dimension, saying: "The nurses were fabulous… just by talking to them and having conversations whether it was about [my son] or not. I think that was part of the counseling too." While many of the parents mentioned other clinicians, such as physicians and surgeons, the focus of the interviews was on the nurses who were primarily responsible for introducing and facilitating photography as part of EOL care.

Data from the interviews highlighted how integral photography is to EOL care as a mediated form of attention that nurses give to both parents and to their newborns as patients. The parents understood the photography as a show of "support" and "care," not simply at the moment of death but throughout a collaborative process with the medical team as soon as they entered the NICU. Multiple parents articulated this process as their "journey," moving through the first hours or days of their child's life, their child's dying, and then their own work bringing that child's life and death forward as they left the hospital. Throughout this journey parents formed "friendships" and "bonds" with the nurses in particular, many of which were ongoing at least up until the time of the interview. Nurses are some of the few people who can respond to many thoughts and questions parents might have but do not feel they can share with others in

their social circle, who understand the experiences through which the families live, and who were present for the life and death of their newborn. In fact, one couple who lived an hour out of town offered to interview at the hospital, a place they considered to be filled with "lots of happy memories" of their son's life, in addition to the more difficult memories surrounding his death; the couple thought of the interview at the hospital in part as an opportunity to visit some of the nurses who were thought of as "friends" who had shared in creating these memories.

Significantly, in EOL care there is focus on the nurses' combined relationship with the parents as well as the child who died (Cholette & Gephart, 2012; Limbo & Wheeler, 2010). Many interviews indicated that one of the ways parents express their relationship with the nurses and their understanding that the nurses had bonded with their babies was through the photos they take and later include in albums to tell their story. In many ways, photography allows the parents to bring forward the special bonds they form in the NICU into their lives beyond the hospital. In the photographic moment, staff and parents come together to tell *their* story, to focus on each other and on the newborn with emotional care distinct from clinical treatment. As an embodied action, photography does not simply capture an important moment, but *is* an important moment brought to focus in an otherwise hectic environment. Speaking again to the whirlwind quality of the NICU, at least two parents retrospectively regretted not taking more pictures of the nurses to include in their memory albums. As one father suggested about the nurses being with him in such a "vulnerable moment": "I wish I had thought to take more [pictures of the nurses] because I would have included more of them. At one point

I wanted to write their names, but then it just got too late and so I never got around to it… They're a really big part of this."

i) "they were… very comforting and support[ive] of taking pictures"

Returning to findings from the first section of this chapter, the fact that parents are new to the spatio-temporal structures and rhythms of the highly medicalized and technologized NICU environment remains relevant here. The "support" parents identified from care-providers was part of grounding or orienting them in the NICU in a way that allowed the parents to make sense of their situation, meet their own needs, and meet the needs of their critically ill newborn. Some parents were cognizant of the vast amount and fast pace of work the medical team were engaged in, and in many ways interpreted actions like photography as a "nice" show of "care" or "attention" paid to the parents above and beyond clinical duties. Of the nurses specifically, one father described the day his son died, saying: "It was all scrambling to get everything. The nurses that day were crazy, they were amazing. They were just running to do everything that you wanted. They would ask, 'Can I get this or can I get that?' and they would just run and get it. That really helped."

A few of the participants also remarked on the nurses' communicating the idea that the families themselves were welcome to take photos in the NICU as well. This encouragement was also identified as an important connection made between the nurses, the parents and the newborn. We can consider one mother's sense of the nurses' work here in her saying "they were very, very comforting and support[ive] of taking

pictures and of spending time in any way we wanted with the baby." In this wording "taking pictures" melds into "spending time" with the baby, which is paramount to understanding how the photography was experienced as the embodiment of "support." The Coordinator picked up on this language again in her sense of the end-of-life care work, saying, "My work isn't just one time, it's a progression and it's about support of the family…." The language of "support" here evokes a material structure that holds up, braces, fortifies, buttresses, as well as an act of substantiation that validates, encourages, consoles and champions—in both senses, the parents are secured in the "chaos" and "roller coaster" feel of caring for their newborn through a critical illness. The notion of "validation" arises here again as particularly relevant, as much of the early work in developing bereavement protocols was based on the discovery that parents have bonded with their unborn or newborn babies and very much desire validation of these bonds (Kennell, Slyter & Klaus, 1970; Hagan, 1974; Klaus & Kennell. 1982).

Being immersed in this environment and "want[ing] to be there 24/7," yet also aware of their need to "give nurses the space to do whatever they have to do," as one mother put it, some parents were concerned their own picture-taking would be disruptive; responses suggested that even if they wished to take photos on their own, parents were more comfortable doing so if the staff gave them the sense that it is okay. One mother said: "I really appreciated that the nurses offered to take pictures and were very supportive that way because then I didn't feel like I was bothering them or troubling them or there was something wrong with me doing this. I was encouraged to, so that felt good. I think it was helpful." This relates back to the point made in the

previous chapter regarding the shift in the nurses' role over the last few decades, from taking the photos to creating an environment in which parents and family feel welcome taking pictures on their own throughout their time there.

ii) "He just showed up one day and took a bunch of pictures"

What brought to light the way in which parents experienced the nurses' support through their taking pictures or encouragement for the parents to take pictures themselves was the discernible difference in the language parents used to talk about their experience with nurses versus with professional photographers. Four of my ten participants had professional photographers take pictures for their family, two within the hospital and two at home where the baby had been transferred for palliation. The photography carried out by family and nurses was spoken about as an integrated part of the NICU experience that was shared by the parents and staff together through their care for the newborn and their cooperation in building a space of attention and emotional support. Having a professional photographer take photos, however, was posited as distinct from these forming relationships. Even a mother who had incorporated photography into her NICU stay in many other ways was hesitant at first to have a professional photographer involved. I understood this as hesitation to have a stranger enter the 'safe' space that they had constructed with the nurses based on mutual respect and shared intentions.

Part of the concern regarded the photos themselves and if the aesthetic would fit the parents' style, but the more pressing concern was whether or not the photographer would be sensitive and respectful. In many cases, the photographer is one of the only

individuals from outside the hospital staff and immediate family who see the baby while in the NICU. Contextualized within the parents own sensitivity to their children looking "so sick" or being hooked up to medical equipment, this moment of being looked at through the camera's lens is incredibly vulnerable. The vulnerability is intensified with the photographer not only seeing the baby, but recording this seeing in a digital image. When asked about her initial feelings about having a photographer come in, one mother ran through the questions she immediately had: "Would they be respectful? Would they be nice? Was it going to be posey? Was it going to be like a wedding photographer? What was that person going to be like and how would we look? How would these pictures be captured for an eternity for us?" In the end this mother was thrilled with both the experience that she called "great" and "amazing," as well as the photos that were "so beautiful." The other mother who had professional photos taken as well in her home was also very happy with this experience, remembering: "I enjoyed it, it was nice to do. I was looking forward to seeing the pictures. When I got the disk they were all good photos." In fact all four of the participants acknowledged the quality of the professionally shot images, describing them with phrases like "beautiful," "they did a great job," "I love these pictures," and "highly compelling images."

Two of the participants (both fathers), however, found the experience uncomfortable and made clear distinctions between these acts of photography and those involving the nurses or families. The first father laughed in thinking back to their time with the photographer, saying he "felt sorry for the photographer": "Of all things to feel on a day where you are losing a child, I actually felt a degree of sympathy for the photographer

in the room." The father understood that this was the photographer's first time taking EOL photos for a family and realized what a task it was to undertake for someone outside of the family:

> Forget about the parents for a second, I don't think anyone…. Gosh, I've noticed across the table that you've had watery eyes at different times during this interview and I don't blame you. When I talk to many people, our story touches them in a profound way… but I did look at him at one point during the interview, and the poor photographer had tears streaming down his face. I completely commend him, he held it all together…. he did an exceptional job… it's one thing to take a great picture, but it's an entirely different thing to take a great picture when you've got tears leaking out of your eyes. I can't remember how long he stayed around for, but past a certain point, I looked at him… our parents had been excused from the room, [the nurse] had been excused from the room after we more of less determined that [our son] was leaving us and it was just [my wife] and I and the photographer and at some point I asked him to leave…There was no push back from either him or my wife. I think at some point when she heard that I had more or less determined that it was time for the three of us to be together… she didn't want any more pictures taken at that point… He didn't argue. She didn't argue. He collected his things quietly and stepped out.

Although there were many details surrounding his son's life that this father could recall with crystal clarity, he could not remember details of when they asked to have the photographer come in, what the photographer's name was, or the details of the

receiving the photos: “I can’t even recall anything relative to when the pictures arrived at their house. I just knew that initially I didn’t feel compelled when they arrived to open the envelope up.” This contrasts starkly to the detail and warm language this father used to talk about one of the nurses in particular who was present at the photo session. He felt he and his wife had “developed a special relationship” with this one nurse in particular and had even asked her to stand up with them at their son’s baptism in the hospital; this kind of “rapport” with certain nurses was not uncommon to hear throughout the interviews. Overall, other than one family who developed an ongoing friendship with their professional photographer, all of the other three participants focused more on the quality of images than a relationship with the photographer when talking about their experiences of this professional photography. In these cases the act of photography seemed more creative than relationship-based, which was integral to the parents’ experience of it. The other father went as far as to say that he “didn’t really care for it.” He expands:

> It’s so nice of [the hospital] to pay for this and everything, but it’s just ‘I don’t know you. You’re not part of this journey’… I didn’t know this guy. He just showed up one day and took a bunch of pictures. It’s just not meaningful… for me it was just much more meaningful when it was driven by us… It’s almost like you want someone who cares to take the pictures… It’s just nicer when a nurse or someone else around just takes a picture.

What these findings intimate is that the parents experienced the photography as a relationship with the person holding the camera. I posit this relationship is most

fruitfully understood not in terms of being either positive or negative, but rather in terms of being ethical, as the camera materializes a dynamic of alterity in which the photographer and the photographed are called upon to recognize each other as other. I would in fact move to replace the language of 'aiming' and 'shooting' a camera that is common in photography with language such as 'extending' a camera and 'offering' a photographic moment. This is not to essentialize the camera as an instrument of love, generosity or responsibility (Levinas), but to rethink photographic mediation in terms of relationships rather than images. I continue this thought in the following chapter, turning to the participants' experience with EOL photography beyond the hospital and in their daily lives after the death of their newborn. Here further relationships come into play as parents call on their EOL photographs to speak and show the narratives of their NICU experiences.

6. LIVING, GRIEVING AND SHARING THE EXPERIENCE OF DEATH-IN-BIRTH THROUGH EOL PHOTOGRAPHS

So far I have focused on the development and presence of EOL photography as a practice in the NICU. In this current chapter I want to move forward to consider the other component of my focusing research question, which is how parents experience this photography in their lives beyond the hospital. In designing my interview questions I was interested in what parents do with the photos in the days, months and years after the death of their newborn, in the sense of how and where the photos are kept, whether or not they are displayed or shared, and how the parents' relationship to the photos changes over time and/or stays the same. In reviewing my interview data and paying attention to the parents' lived time in the NICU versus *after* the NICU, I noticed the responses shifted in focus from the photography as (inter)action, to the photos themselves as representational images and/or as material objects.

In the first section below I present three themes that emerged around the parents' experiences with the EOL photos after the death of their newborn: the photos as healing tools in what I term creative grief work, the 'thereness' of the photographs as material objects, and the immense value of the images that correlated with an intense fear of losing the digital image files. In the second and third sections of this chapter I turn to the findings clustered around the theme of 'sharing and showing.' The second section deals with the parents wanting their other children to "know" their deceased sibling through stories and photographs and the third reports findings around how parents expressed the ambiguity of making their EOL photos visible to people outside of their immediate family. While there was a strong desire to tell their story and "show

off" their son or daughter, there was also a profound concern for maintaining "privacy" and "protecting" their newborn from others when the intention of "seeing" or reception of the images was not always clear. What many of the parents described was a kind of emotional work they felt they needed to do to support other people through the "difficulty" of seeing the photos of their sick or dying babies.

6.1 Bringing the Photos Home

My intention behind incorporating a Photo Elicitation technique into the interviews was to have the opportunity to see the photos, rather than just hear the parents describe them in language, as well as to have the photos available to ask questions and prompt memory in ways that might not be possible in an exclusively spoken interaction. Another aim in having the photos present for the interviews was to observe how the photos were seen, displayed, touched, and gestured towards throughout our conversations. In the end, eight of the ten participants had printed and arranged selected images into a photo album in the months after their newborn's death, and seven of these eight brought their albums to the interview. The one participant amongst these eight who did not bring her printed album (because we interviewed at her workplace) still had a digital album of photos available to look at on her smart phone. Of the seven printed albums I was able to look through in the interviews, all were arranged in chronological order, with parents often commenting if they noticed one of the photos being out of order according to how they remembered the events.

As I opened the interviews by inviting the participants to tell me about their

family, all of them who had albums would open it up, introduce their son or daughter, and start their story from the beginning: the pregnancy and birth story. We would look through the pages together, sometimes with me pausing on certain pictures to ask a question and sometimes with them pointing out details or having the photos jog a particular memory. I noticed that in the one interview in which there was no printed album present, looking at the pictures on the cellphone screen did not feel the same as looking through the printed pages. Both myself and the participant interacted with the photos quite differently than was typical of the other interviews, thumbing through on the screen more quickly than one would with the pages of an album. The smaller screen also made it harder to see details or have multiple pictures juxtaposed beside each other. This is not to suggest these photos were any less significant for the participant—it was obvious they were extremely important to this mother and her collection of professional black and white EOL photos were strikingly beautiful—but rather to highlight the way in which different image technologies elicit unique interactions. In another interview, a father who also did not have a printed album assembled (neither in the interview nor at home) still brought seven family photos with him to help tell the story of his family. As the interview started, he laid them out carefully on the table, arranged almost as playing cards or Tarot card spread. As I turned on the voice recorder he began speaking immediately without my prompt: "I think probably the best way to start is to give you the full context and the history of the situation…" As he began his narrative, much like the other parents, he would occasionally point to one of the photos he had laid out, as if to introduce the characters in the story. Although there were no pages to flip through as

with an album, I found we both stared at the photos on the table often throughout the interview, especially in moments of silence that somehow felt filled up by the ideas and anecdotes that had been associated with the various images. In analyzing the interview data, it was interesting to bring together some of the participants' responses on their initial hesitation around the EOL photography with my notes on their handling the photos in the interview, which exhibited great care and attachment. While all ten participants had declared the value of having the photos, their reaction to and interaction with the photos provided even more insight into the embodied nature of this value, not as an external status assigned or granted to the images, but experienced as part of the photographs' existence in their life-world. In the following three sub-sections I will discuss more findings in relation to this idea.

i) "I just felt like I had to get this done"

I was immediately struck by the care and effort all of the parents had evidently put into making the albums they brought to the interviews. Some of the albums had even been crafted as scrapbooks, with colourful titles, stickers, backgrounds, and trimmings. One mother had made an occasion of assembling her album: "I wanted to do something more cheerful on her anniversary rather than just sit and cry so I had this idea to do a scrapbooking party. I have some friends that scrap book so they came over on that day and so they made some of these pages." Note the way she contrasts "just sitting and crying" versus "doing something" in relation to this later statement she made: "When I look at these pictures, it just brings me back to that time and I feel very sad." While

looking at the images was associated with simply sitting in sadness, the scrapbook helped transform the photos from images to look at to an activity to *do* and something to *create*. Working at something seemed to provide a sense of moving forward versus a kind of stasis in sitting still and immersing oneself in the loss of the baby. Another mother mentioned the feeling of needing to do something when her son first passed away as well, which she related to being home on a three-month maternity leave without the care of a newborn to fill her days:

> afterwards I got fully bored and thought 'I need to keep myself busy. What can I do?' First of all I thought 'maybe I should go volunteer at [the hospital] because I'd be close to where I was a month ago,' but then I thought I wouldn't be in my right mind set to do that and so I thought 'Okay, what's something that I could do at home and still be close to him?' So I made this.

For another family it was a matter of finding the perfect frame for their favourite photograph of their son. The father recalled the words they said to their son as he died and how they were always reminded of these words by the one photo they displayed in their home:

> We said 'you are leaving us, so we are going to live for you and we are going to live a little more, we are going to love a little more and we are going to laugh a little more.' About 3 months later my wife found this picture frame with those words on it and she came and showed it to me. I almost broke down because these were the exact words, the exact promise that we made to him on the day that he left us. We've tried to live that philosophy. We've tried to do exactly that

for him.

Some of the parents made other things in addition to their albums or framed photos, like special displays on book shelves in their home, carefully curated memory boxes, and other collections, as one father was excited to share:

> We've got bigger pictures blown up and put in frames on our wall. We have bookshelves that have his ashes and the molds that we did and the casts and some more pictures. There are a few things I bought like a baby board that has his name with the saying on the back. We have a Maple Leafs jersey with his weight on it and that's framed in a shadow box. We've got lots of stuff.

About the shadow box he goes on to say: "It was a project that I wanted to do. We had the shadow box, but I never got around to it and then I think [our second child] was almost due and I was like 'I haven't done this yet.' It was like a two day project and I just felt like I had to get this done." This feeling of having to make something resonated with the responses from the father mentioned in Chapter 5 who had assembled his photographs into an intricately detailed slideshow, complete with edited transitions, music and captions—a project he called a "labour of love." The Coordinator had mentioned as well that after leaving the hospital many of the parents send her pictures that they have creatively altered:

> I've seen dads especially who will do the highlighting of just the face and everything else is in black or putting everything in black with some pink colouration around or blue colouration for a boy. They have sent me back these pictures and they are stunning. Because again, it is part of their grief work…

because they have to *do* something.

I posit that the connection between the parents' creative work of editing, arranging and/or altering their photos is not incidental to their movement through grief. Key here is the notion that grief is not only a psychological response, but an embodied response constituted by actions, reactions and interactions. I want to distinguish this mention of embodiment here from psychiatric research focused on the somatic aspects of grief. I further want to clarify that my use of the term "work" to describe the parents' use of the photos is not exclusively based on Erich Lindemann's acclaimed concept of "grief work" which he defined as the work one does to achieve "emancipation from the bondage to the deceased, readjustment to the environment in which the deceased is missing, and the formation of new relationships" (1944, p. 145). My approach rather aligns more closely with Davidson's sociological conceptualization of "grief work" in terms of *relationships*, as she proposes:

> Griefwork includes psychosocial emotional labour (Strauss et al. 1997; Bolton 2000; James 1992, 1998), both in the relations between caregivers and patients, and in caregiver-to-caregiver relations, as well as non-medical instrumental work such as planning, organizing, negotiating, and 'doing' what is necessary (Strauss et al. 1997) to carry out the bereavement protocols. (Davidson, 2007, p. 182)

I build on these ideas to acknowledge the way in which this "doing" is carried out through cultural material objects that are taken up as tools in this emotional labour. More specifically, my interest is in the use of photographic media in this capacity,

which was exemplified in my participants' experiences. Because this kind of grief work involves symbolic meaning-making as well as material objects, I put forward the term *creative grief work* as a way of capturing all of the dimensions that my findings revealed. I want to highlight the phenomenological dimensions of creative grief work in the sense that the media production these parents were carrying out can be understood as a process by which they are not simply expressing or representing a loss—which typically defines "mourning" (Fulton & Bendiksen, 1994)—but are extending their embodied grief through technologies, transforming the loss into presence, and giving meaning to their lived experiences through a creative process. From this point of view, equating photography to death and/or mourning seems strikingly limited. Again, if we think about these extensions, processes and labours in terms of desires as opposed to technologies as Batchen inspired, then we see how digital photography is a difference in degree, not in kind in relation to film photography. While both involve the photographic desire to make present the relations parents and care-providers formed with the newborns and with each other, digital technologies allow for more re-presentations to be made, more images to be stored and for images to be more mobile and versatile in creative grief work.

Let us return momentarily to the mother above who seemed to contrast a stasis in "sitting and crying" or "looking at" the photographs with a more active "doing" something with the photos. I want to explore this a little farther in order to break apart what on the surface looks like a duality between "doing" as productive versus "looking" as a passive stare. The language of being "productive" brings to mind the re-productive

nature of the creative and emotional labour taken on by the families; re-production, in any form, is a process oriented to the future, the making of something new that moves forward and changes the state of how-things-are. The interview responses suggested that the process of "looking" was very active and very meaningful for the parents. One mother's language around this was particularly helpful to make this point: "At first, I was looking at the pictures as my healing tool, because the first four months I cried quite a bit." The term "tool" both reveals the "looking" as an action extended through the photographs as media, as well as the language of "healing" implies a progression through grief. Even the mother above who found herself "sitting and crying" later concluded: "… every year as I look at [the album], it gets easier. It doesn't feel quite so overwhelming." The "looking" here seems imbricated within an active process of healing, not calling on memory or mourning exclusively but in conjunction with imagining, feeling, projecting, and changing. This evokes Olin's reading of *Camera Lucida* mentioned in Chapter 2, which shifts focus from Barthes' deceased mother—who he was claiming to mourn—to the way in which his written "vigil" was bringing her into his living process, a process of becoming Barthes experienced through his narration. Other participants also touched on the idea of their relationship with the photos as dynamic, with their interpretation of the photos and the desire to look at the photos fading somewhat over time. Another mother talked about this in terms of why she had added her professional EOL photographs to the collection of the personal photographs she had on her cellphone:

> to be honest with you, every single night after he passed away, I would look at

> the pictures on my phone… not just night. Whenever I was laying down and couldn't think of anything else, I would just look at the pictures. I thought "You know what… I want to see these too… these [bereavement] pictures as well," so I added them to my collection… Now, very seldom… The first year, yes, I looked at them almost every night. I needed that. Then slowly, it wasn't as much as I used to.

These experiences counter Barthes well-known position that the "violence" of the photograph is that "i*t fills the sight by force*, and because in it nothing can be refused or transformed" (1980 p. 91, emphasis in the original). While the referent may always remain within the image, the meaning one makes and the embodied relation one develops with the photograph is not destined to be "a strange stasis," despite Barthes' contention (p. 91).

ii) "I have hundreds of photos and I like to look at them because I remember and feel like she is with me still"

When I asked each of the participants about where they kept the photos in their homes, I noticed they would often gesture as if in the room they were imagining, pointing as if the photos were right "there." The language and gestures that I categorized under a theme of "thereness" point to the significance of the photos not simply as symbolic content but as material objects. When parents talked about where they kept the photos, there was attachment to having the photos "close by" or "at hand." Most significantly, having the photos did not always relate directly to being able to look at the images, but was more about the comfort of the photo-objects just being *there*. This idea came across

clearly in one mother's response, who had only looked at her photos once since the NICU: "The thought of having them is extremely comforting to me. It is. But do I look at them? I don't." Here the "having" of the photos does not equate to "looking at" the photos. When we explored this further in the interview, she explained:

> there is that comfort there that I have all that stuff. Even though I don't look at those pictures all the time, the fact that I have them, to me, is comforting because it's a piece of him. The fact that I have his little blankie is a piece of him. I have the teddy bear. I have this and that. Those are all pieces of him. If you didn't have them, it just doesn't complete the whole picture… the whole experience.

It is interesting here how she thinks of the "experience" in visual terms of a complete picture, which might point to why she did not look at the photos. At another point in the interview she had mentioned that she was more comfortable with the mementos that she kept out in the room that was supposed to be shared by her twin sons but now belonged to her surviving son alone. She even had her ultrasound image of the twins displayed by the crib. The EOL photos, however, "said so much"—too much—about her son's "illness" and "suffering" that he "did not deserve." Still, their physical existence nearby was experienced as a "comfort." When I asked where she keeps the photos, she said:

> …they're tucked away. They are in my bedroom. They are in a spot where I keep all my kids' SIN numbers and that kind of thing. I had them in my son's room initially and then I took them out because I'm like 'If I ever want to just view them when they are napping, I don't have to go into his room. They are

closer to me.'

The proximity and presence of the photos here was a substantial part of her experience with EOL photography, as it was for other participants. Another father who was "not compelled" to look at the photos still pointed out that he and his wife knew exactly where they were and they were not simply stored "in boxes in the basement" like other family albums might be. Even the photos that were not out or displayed were thoughtfully kept "close by," as it was for another participant who said this:

> We have an ottoman in the living room, so [the album] is just in there. They are on the laptop as well so you can pull them up anytime. Specifically, I went out and got the hard drive so I could back it up… It's basically beside us in our family room. It's on our end table or on the ottoman.

This same participant went on to clarify: "I don't think I've opened the book for quite awhile and gone through them, but you walk in the living room and you see the cluster of pictures. You're always thinking of him." Here it is important to distinguish the photos that were stored and accessed and those that were displayed all of the time. There was great care put into deciding which photos to keep out and how or where they would be arranged in the home. It might be useful to reflect on the way families actively display or hold back their images through Kember and Zylinska's notion that photography is "productive and performative," and an active process of "cutting," as explained in Chapter 2. The families are giving to, taking from, interrupting, and interacting with the space-time of their lived environments by introducing the photos or keeping them unseen; the photos here are not mere objects or representations added to

the background, but are part of a becoming.

Some parents only had one or two photos exhibited in their home, while others had many up, like one mother who said her pictures were "pretty much wallpapered." Amongst the parents who only had a few photos up in the house, it was most common for them to be "propped up" on a dresser beside their bed or hanging on the bedroom wall. Putting the photos in the bedroom would imply, perhaps amongst other things, that they were meant to seen primarily by the parents rather than for people coming in and out of the shared spaces in the home. The couple who had found the special 'Live Love Laugh' frame was quite intentional about placing the one photo they had up of their son in the bedroom, as the father declared:

> We keep this in our bedroom. We don't display anywhere else in the house. We've put it very deliberately in the frame and very deliberately this shot to capture that image and that point in time and that special moment. As much as he'll always be live in heart and mind… this is the one picture of him that we keep around the house and we keep it in our bedroom in a spot where it doesn't necessarily attract much attention for anyone coming in… but it is something that we keep there.

The "special moment" he is referring to here is of the baby boy grasping his mother's finger as she reached into the incubator; this was mentioned in the previous chapter in terms of a moment in which his son was "living" not "leaving," which is why the couple thoughtfully singled out this one image to display in their home.

I will discuss the significance of exhibiting the photos at home in terms

"sharing" with other people in the second section of this chapter, but for now want to focus on the photos that seemed to be put up in the home more as a way for the parents to connect or mediate the physical presence of their newborn from the time when the baby was living to the physical absence of the baby in the home. Sections of the interviews reveal a complex relationship between the parents, the newborns and the photos, experienced by the parents in terms of presence and absence more so than the photos being "happy" or "sad" representations. One father talked about what the images meant to him in these terms:

> It's all I have of her… That moment lives forever and no one can take that from me… I guess that's the beauty of photography... It's a split second in time, but every time you see that picture… maybe for a brief moment, you feel like she's there again or she's alive, even though she's not.

Another mother mentioned a similar experience, saying:

> I have hundreds of photos and I like to look at them because I remember and feel like she is with me still. I don't know what I would do if I didn't have the photos. I would feel like she wasn't really there or there would be something missing… having just the mementos and not the photos.

At another point in the interview, this mother returned to the distinction she perceived between the mementos and the photos, aligning with the father above who felt the photos in some way felt like the baby is "there again" or "alive":

> No, they do stand out because it is like... it's different to actually be able to see her. I remember after I finished the scrapbook… about one year after, I was

> looking at all these photos and wishing I had more, because it feels funny. When you have photos of somebody alive, you always have more photos and there is always new things to look at, but with her, I just felt like I wanted more and there wasn't any more… and then I was cleaning out some email and I found an email from [the bereavement coordinator] that had a bunch of photos that the nurses took. I was so excited because it was something new. It was like bringing her alive again. It's definitely different than a blanket or another memento.

This is an interesting experience to bring together with a response from the father who articulated the pain of not having any new images materialize after he had spent much time arranging his photos into the slideshow: "The hard thing is… what do you do when you run out of material? I can't keep making these."

There are a few points to pull out of the last idea above for further consideration. One is that receiving "a bunch of new photos" is something that was not likely to happen when EOL photography was carried out only on film cameras and fewer frames were shot. As discussed, digital technology provides a much more prolific capture—through many images on each memory card as well as a proliferation of devices through cell phones and so on—that changed the nature of EOL photography from the provision of a few memento snapshots to the provision of hundreds of images. In many ways, having many images, especially if snapped in succession, mimics the way in which cinema is essentially the insertion of still images into a format that makes the frames appear to be moving by way of their appearance one right after another. This sense of movement was particularly important for one mother who asked the nurses to take as

many photos as possible in order to share them with her mother overseas: "[the nurse] was just clicking away and my mom was telling me 'In every picture, I see his hand in a different direction.' This kid was fiddling or moving every second. That's how we kind of talked about him."[20] There is an element of animation here that feels like life—in the sense of our lived experience moving through space-time—which again challenges the ontological assertion that photography is always only a slice of time, that it *is* death: What if we choose to focus on the way in which photography animates time that has passed through a materialized present/presence rather than think of it as a media that "embalms time" (Bazin 1960, p. 8)? Even Barthes' phenomenological study of photography overlooks this animation, suggesting of photographs "there is always a defeat of Time in them: *that* is dead and *that* is going to die" (Barthes, 1980, p. 96). Barthes conceives a certain "madness" to photography which is that, phenomenologically speaking, the photograph paradoxically contains "not only the absence of the object" but also "the fact that this object has indeed existed and that it has been there where I see it" (p. 115):

> The Photograph then becomes a bizarre *medium*, a new form of hallucination: false on the level of perception, true on the level of time: a temporal hallucination, so to speak, a modest, *shared* hallucination (on the one hand "it is not there," on the other "but it has indeed been"): a mad image, chafed by reality. (p. 115, emphasis in the original)

[20] It is interesting to note this mother also teleconferenced with her family overseas via Skype during the religious ceremony she carried out after her newborn had died. While this dissertation only focuses on EOL photography in terms of still images and only one of the participants had experience with this, future research will certainly explore the other technologies being introduced into the NICU.

In my opinion, the "hallucination" set up here is grounded in a phenomenology that falsely dichotomizes absence/presence and object/subject, overlooking the in-betweenness of attachment that is not simply emotional but is fleshy and affective in its way of connecting bodies across space-time. Perhaps the in-betweenness of pregnancy itself as a state of being serves as an apt metaphor for the way in which images are both pregnant with the subject, as much as the subject is pregnant with the meaning and feeling of the image. I am thinking here of Francine Wynn's description based on a phenomenological study of women's accounts of pregnancy, in which "[t]he baby–in-the-womb bears the mother as much as the mother-to-be bears the baby" (Wynn, 2010, p. 5):

> the baby-in-the-womb is a pre-infant from the start, and that during pregnancy both mother-to-be and her pre-infant are modified through their intertwining and spreading away. Pregnancy is an unfolding, chiasmic relating that constitutes a futural preparing of both the mother and the baby-to-be. Pregnancy is delineated as a chiasmic relationship in which there is a simultaneous holding/being held of both mother-to-be and the pre-infant. (p. 5)

Wynn's phenomenological frame is not meant to essentialize pregnancy, but to "sketch out the possibilities for bodily interinvolvement" (p. 4). Because the mother and the unborn baby are never two separate body-subjects but are also never entirely one body-subject, they are in a process of becoming-together that blows open any subject-object, dead-alive, absent-present constructions. The absence-presence of the newborn that parents experience via the EOL photo-object was complicated but palpable in the

interviews, and can be interpreted as an example of one "possibility for bodily interinvolvement." In support of this argument, consider one mother's words around the EOL photographs her and her husband kept on a shelf in their living room: "[Our daughter] is with us, within us. She is gone in the physical way, but it doesn't mean that she is gone. She's our child… We have [her photo] in our curio. She was supposed to be somewhere in the crib, but she is in our curio. She has her shelf. We have it almost accessible. It's here."

Though edging outside the scope of my research, it is worth mentioning that it was not only the photographs that acted as a medium for the baby's absence/presence. One mother shared her experience with this:

> For a while I think I slept with her blanket because it still smelled like her. All her clothes I left in the drawers because we were expecting her to survive. We had been planning for her to come home, so I had all this newborn clothes and kept it in the drawers. I think after awhile when the smell went away from her blanket, I stopped sleeping with it and I put it away and I packed away all the clothes she had worn at the hospital and I put it (I know this sounds crazy) in a Ziploc bag. I would open it sometimes so I could smell her. I remember the first time I left the house I felt like something was missing after she died so I got one of her little hats and still carry it in my purse.

I include this response to expand the definition of 'media' from traditional media forms to any material object involved in sensual experience made meaningful as part of an individual's life-world. I will continue this thought below in relation to the

photograph's materiality exceeding their symbolic content in the participants' life-world.

iii) "If you know you can never take another picture of your child, you want to know the pictures are safe somewhere"

In film photography, the image activated on the negative is barely legible, so requires chemical processing and transfer to photo paper before the full detail of the picture can be discerned. What is unique about digital photography, however, is that the digital file can be seen on the camera's preview screen or on a computer screen without needing to print the image. Therefore, while many of the examples discussed above dealt with printed photographs, it is equally important to acknowledge the way in which the participants experienced the images as digital files. In many ways the digital nature of the EOL photography in which they participated allowed the parents to carry multiple photos around with them more easily, or perhaps more discreetly, than it would be to hold a handful of printed pictures in one's bag or pocket. Participants talked about storing many or all of their images on their cellphones or laptops to take out into the world with them every day. For example, one father had shared his photos with a close friend at work and then slipped the DVD of images into the daily planner he carries to work every day. He explained that he "never took it out, so in some metaphorical way, [my daughter] is with me everywhere I go because that binder goes with me everywhere." He stored the images in many other different locations as well, saying: "It's kind of weird, so I've made multiple copies of these. There is one in my DVD player all the time. I don't know… sometimes I think I'm crazy." What my findings

uncovered, however, was a very common practice of storing the digital EOL photo files on a number of devices in different locations. When I probed at this, parents language turned to sensations like "fear," "paranoia," or being "terrified" of losing their images. In asking the father above about storing the images in different place he tried to explain: "To ensure that… I would de devastated if I lost my last copy of that. It's a piece of… I don't even know… and yet I would be devastated."

Notably, fear around losing the images was not expressed as much in relation to losing the printed images or albums themselves, but rather was almost always a concern around the digital files. One exception was a mother who mentioned the fear of losing everything:

> I've said to my husband 'If the house burns down, I'm grabbing [our daughter] and I'm grabbing like….' we got a really beautiful album made and we have a disk that every day I say 'I have to put it in the safety deposit box,' but I have it downloaded and we have extra copies downloaded to certain places because once they are gone, you'll never get it back.

Regarding the digital files specifically, she continued:

> I have them backed up on different computers. I have them burnt to different disks. I have them saved at different people's houses, like family, my mom, my dad. Because I'm so paranoid that once they are gone, they are gone. I have them on this phone, but I had them on my other phone and I always have my IT guys transfer them because I'm terrified that I will lose that. Not that I can't get them reprinted, but I'm just saying that if you know that you can never take

> another picture of your child, you want to know that those copies are safe somewhere.

It is interesting that although she realizes she could reprint the photos from her hard copies, the fear and desire is attached to the files themselves. This might be accounted for because, like most parents, she did not print all of the many photos that had been taken; the fear is not just around losing *all* of the photos, but around the idea of losing even just one. The fear of losing the photos that were stored on a cellphone emerged in another interview as well: "I had to change cell phones and I was very adamant and said to my husband 'I don't want to lose any pictures' because I knew I had those pictures." The pictures she is referring to are the only few images that were taken of her son right after he was born and still looking "healthy," as the mother put it. There was a certain incongruity in that many of the parents first, only or "favourite" photos were taken on their cellphones (because it was often the only camera available around the time of labour and birth), yet the cellphones also felt like precarious devices upon which to store these extremely "valuable" or "precious" photos. Even with tablet computers, the mobility of the device was both an advantage in having a camera at the ready but also a drawback when it came to ensuring the safety of the images. One father unfortunately discovered this too late:

> I've got them all backed up on an external hard drive… The only thing on this hard drive is his pictures and videos… I lost my iPad or the iTouch. I had some more last pictures of the day, but I hadn't uploaded them to the computer, so I don't know what happened to them. I really regret and kick myself that I didn't

get those off right away.

Our discussions about the fear of losing the photos also inevitably involved the exceptional value of the images, on which all parents were unanimous. One mother used the term "prized possessions" which seemed to accurately capture the feelings many of the parents expressed about the photos. She declared: "I think you'll find in your research that for parents who have children who have died, you value these things more than anything else." Another father also offered this thought: "The tough part is that this is all it will ever be because she's gone. So it makes it that much more valuable or precious."

6.2 The Role of EOL Photographs in Helping Other Children "Know" Their Deceased Sibling

Above I have reported themes around the value of the EOL photographs in terms of the way participants interacted with the photos on their own in their daily lives after leaving the hospital up until the time of the interview. What also emerged from discussions around the parents' time after the NICU, however, were their meaningful and multifarious experiences with "sharing" or "showing" the images to people after the death of their newborn. Generally speaking, the interview responses indicated a distinction between the experiences of sharing images within an immediate family or with "close" friends, versus sharing with more extended social groups, like colleagues, religious communities, or more distant family and acquaintances. Overall, having the images seen by people outside of their immediate family was expressed as a

complicated experience that was both decidedly important to the parents but also at times very difficult to navigate.

i) "The photos will definitely be a part of [our daughter's] life and knowing about [her brother]"

As mentioned in the previous chapters, not all families are immediately eager to participate in the photography as part of their NICU stay. Even families who decide to have the pictures taken do not always take the photos home with them right away or at all. In these cases, the EOL nursing team files the discs, any printed photos and any other keepsakes that were gathered for at least a few years, with the understanding that families might eventually return for them. The Coordinator recounted a powerful story in which one mother returned to the hospital years after her daughter had died looking for any photos the hospital might have. Fortunately, the Coordinator was able to find the mother's file, not only containing photographs but a blanket, a gown, a lock of hair, a hat, booties, and a clean diaper that would have been the size of the baby at the time. The Coordinator relayed their conversation:

> So she got here and we sat down and talked and she said to me 'I'm amazed you've kept all of this. This is just such important stuff for me.' I found out… that her daughter had actually died 10 years before, so these were not the best pictures, but they were pictures. I said to her 'Can you explain to me why this is important to you now?' She said 'When my daughter was born, she was my first born, I didn't speak English, my husband didn't speak English, and a nurse who

> wrote me a letter in Chinese wrote in the letter that they had these pictures from my daughter, but I couldn't get them before now. My English is now good enough and I can actually talk to you… My son is now eight and he has asked me if he looks like his sister and I can't tell him.'

In this conversation this mother went on to say how helpful she thought the photos would be to her healing and for her son to have answers about his baby sister, even years after the newborn's death. I start with this anecdote because of its deep resonance with many of the responses from my interviews as far as the role EOL photographs could play in the life of bereaved siblings. Of the 10 parents I spoke to, five had young children at the time of their newborn's death, and two of these five also had a surviving twin. Three of the parents had more children after the death of their newborn. For all of the participants who had surviving children at the time of their loss, there was a tremendous focus on three main concerns: first was securing the surviving child's experience in the NICU to ensure he or she felt safe and supported around the death of his or her sibling; second was ensuring that in moving forward the child understood what had happened and had healthy outlets for his or her grief; and third was finding ways to help the surviving child "know" his or her sibling as part of the family. It is on this last point that the photography most often came into play. This was prevalent as well for parents who had other children after their neonatal loss, wanting to make sure the newborn was someone the other children "knew" as a brother or sister. It was interesting as well that looking at the EOL photos in relation to their surviving children was also a process through which the parents also came to "know" their newborn in

new ways. We see this one mother who was taken back in the interview as she looked through the album: "Looking through these pictures, he looks a lot like our daughter. I'm seeing such similarities now because I haven't looked at them in awhile." For another participant, it was not always a positive experience to look at the photos of her newborn son and seeing similarities between him and his surviving sister who was born in the year after his death: "sometimes it's really hard to actually look at these pictures especially… when my daughter was born, my husband and my mother in law would say 'She's just like her brother. She resembles her brother so much.'"

Participants talked about their own experiences melding with their surviving child's in ways that brought to surface the complexity of moving through bereavement with a young child. For one, parents talked about carrying both their own feelings and that of their children in their care. As one father put it, trying to "balance" all of these feelings "sort of took things and amplified them somewhat." Part of this amplification was a certain push towards recovering from the grief or, as one mother put it, feeling like she did not "have an alternative other than to get through that" because "you don't want that to affect the other child." One mother thought of her surviving children as the "therapy" that helped her through the situation, saying: "I didn't need to go on those [memorial or community group] websites because those kids were my therapy and they still are… I was busy with my kids. That was my focus and that's where I want it to be. What better counseling is that!"

Another balancing act that came to light was the parents' efforts to have their surviving children "know" their deceased sibling as a member of the family, while also

making sure the death of the newborn was not an overpowering force in the family's life together. As one father said of his daughter who was five at the time of her baby brother's death: "We've always been very, very careful to keep an eye on her and make sure that she's growing up the right way and that this doesn't hang over her or define her… and it hasn't. She's a very happy little girl." This father—who had gone on to do extensive volunteer work with an organization focused on helping children cope with the death of a sibling—also reflected on the idea that he and his wife did not want the death of their son to define the family as a whole:

> As parents we want to be defined more by the two kids that are still with us, as opposed to be defined by the one that has left us… We have to focus our emotional strength on being the best parents we can for [our daughter] and [our son]… there is a time and a place for grief and mourning… we were going to do that, but we weren't going to let that overcome our obligation and our responsibilities to be loving and caring parents.

Another participant shared a similar thought:

> I feel like sometimes when people go through things they're like 'I'm a survivor, I survived this, this is my identity. And we didn't want… you know for [my husband] and I, Graydon is something we think about every day, every second of the day, but for [our daughter] we needed to make sure that yes, she has a brother, her brother is dead, this is very sad… so for us we have [the pictures] there, she knows, but we didn't want it to be at the forefront of her mind, it's always something at the back.

We return here to the idea of the photos being "there" in connection to her daughter "knowing" the newborn. In many of the responses, "knowing" was cultivated through telling stories and showing images of the newborn to the sibling, integrating the EOL photos into the family's life-world. In some cases if the children were old enough to remember their sibling they would ask to see the photos, as one mother explained: "we have lots of pictures in our home… it's hard because he's not with us, but [my daughter will] say 'I want to see this picture. Oh look his eyes are open.'" Two other parents mentioned how their surviving children would sometimes surprise them by acknowledging their sibling out of the blue, as with one daughter who all of a sudden "blew a kiss in the air" or another who would talk about how much she missed her baby brother. In other cases where the surviving child was still too young to remember the newborn or who were born after the death, the parents were already anticipating the role the photos would play in their family, as one participant exclaimed: "I will definitely show [the photo] to [my daughter] once she starts understanding and grows a little bit older. We're comfortable with sharing our memories with her."

Many participants used the language of not wanting to "hide" their newborn, either within the family or more widely. Here the photos intertwined with the spoken narrative in key ways, as we see with this mother who was very focused on forging some form of relationship between her surviving daughter and her deceased son: "We like talking about him, so I think we're going to make sure she knows. Every night I talk to her about him… The photos will definitely be a part of her life and knowing about him and stuff." This participant and her husband thought of showing their

daughter the photos as part of a declaration that they thought of as the opposite of "hiding" the death or "keeping it a secret": "We're more like 'He was our son, he is our son, he's part of the family'." To ensure their son was always present as part of the family, this couple also incorporated their EOL photos and other mementos into other professional family photography sessions. The maternity photos taken for their second pregnancy involved the blanket "that represented him, that he had in all the [EOL] pictures," as well as other EOL images placed throughout the portrait sittings, "so he was included," as the mother articulated. This is a curious statement, as it points to the newborn being present in the family more so than simply being re-presented through stories and images.

For one of the mothers I spoke to, having her surviving children "know" their brother was a particular motivation for having the EOL photos taken in the first place. She was already thinking about a future in which the pictures would be valuable in this way while in the NICU, despite her initial reluctance:

> I knew that it would make sense and I knew that right now I'm going 'no, no, no,' but I knew that one year or two years from now… and I knew that my kids needed to know him too… and this is part of knowing him. I know that when they get bigger, we will all together look at those pictures.

We can contextualize her process of deciding to have the photos taken within the findings from Chapters 5. Through this participant's experience we see one possible outcome of the having the nurses use the photography to gesture towards a future beyond the NICU that parents might not be ready to think about while immersed in

critical care. On a separate but related note, the idea that she would look at the photos with her children at some point in the future was a profoundly important aspect of not only this mother's experience with the EOL photography but also her experience with this research study as well. She mentioned from the outset of our initial correspondence that she had barely looked at her EOL photos and she did not want to bring them to the interview. Throughout our conversation she mentioned that she was working towards a point in her grieving process when she would print one of her photos and frame it for her surviving son's room, which already had other mementos of the boy's twin who had died in the NICU:

> We will get to a point where we will all know those pictures. I just think my children are way too young. Even my four year old, I don't think she's ready for that. Even though the innocence of a child... I would love to see… she won't see the illness. To her, it'll be a baby. Like I said, my goal is to put that picture up on a frame and display it.

At the time of the interview all she felt she would see in the photos was a "critically ill baby," which reminded her of his "suffering"; incidentally, this was a feeling another father voiced as well, who also did not display any photos of his daughter in his home: "I don't know if I can handle having a picture of her up… When I see pictures of her, she just seems like she is in so much pain. I don't want to be reminded of what she had to suffer." This mother, however, eventually came to a different conclusion about her EOL photographs, which she shared with me in her reflections on my summary of initial findings a few months after out interview:

> A few themes that were highlighted in your study continue to have a huge impact on my daily life. The pictures that I have of my little angel will help me in the healing and grieving process. In fact, I have shared one of them with my daughter just recently. She was so happy to see her brother for the first time. The joy in her eyes made me realize that these pictures cannot just be viewed as a source of pain and hurt. Although I am not emotionally ready to view or share all of [my son's] pictures, I have a sense of peace knowing that they are in a safe place. And when that time comes, I will embrace all of them.

6.3. Sharing "Difficult" Stories Around a Newborn's Life and Death

Existing clinical research has shown that although grief resolution is largely aided by support from family and friends, individuals facing neonatal or perinatal loss often feel as though their grief is not validated nor that they can talk to people about their experiences (Peppers & Knapp, 1980; Lasker & Toedter, 1991; Ujda & Bendiksen, 2000). Layne has explained this "silence" around reproductive loss in sociocultural terms, researching American pregnancies specifically but with findings that translate to a Canadian context. Layne maintains that "the medical management of reproduction" has "moved up the time and pace with which many US women begin to socially-construct the personhood of a wished-for-child" (2000b, p. 322). Identifying another "cultural force" at play, Layne asserts that

> [w]hen the pregnancy ends without a baby to bring home, the very people who have encouraged the mother-in-the-making to take on this role and may have

> participated with her in the social construction of her 'baby' often withdraw their support for these interrelated projects, and act as if nothing of any significance took place. (p. 323)

Layne uses this argument as the basis for her analysis of the material culture of reproductive loss, within which bereaved parents construct their social identity as parents and the social identity of their baby (1999; 2000a; 2000b). My interview questions did not presume that parents had experienced any sort of social silence, nor were my questions weighted with the language of "silence," "taboo" or any other components from the existing research; yet, when I asked about the participants' experience with sharing their photos, certain themes recurred across the interviews that made sense against the backdrop of existing findings on the "realness problem" (Layne) of reproductive loss. What was missing from the existing literature that my study brought to light, however, was the way in which the dynamics of this social silence are experienced through EOL photos specifically as part of the material culture parents use to construct their identity as parents and the identity of their newborn. I report my findings on this below, highlighting the way in which new media technology has impacted the construction and circulation of these identities.

i) "Part of the reason I'm here today, is that I don't keep any of this a secret"

As mentioned in relation to siblings above, at least seven of the 10 participants spoke about how important it was to them to not feel like they were "hiding" the fact that they had a newborn who had died. One father touched on this idea directly, acknowledging it

as part of his motivation for participating in the research:

> Part of the reason I'm here today, is that I don't keep any of this a secret. I don't feel badly about talking about it. For me, I would feel somewhat unusual if I tried to hide this away or keep it from other people. I'm proud to be a father of three. I feel terrible that I'm only raising two, but I don't keep it a secret. As I said earlier, in some respects, the loss of a child has made me a better and a stronger person.

For many of the participants, not "hiding" the newborn's death meant "showing off your kid," as one mother put it. As for many parents in North American culture, this "showing off" involved showing people photos of their baby. One mother who had placed one of her EOL photos on her desk at work said: "Of course you always want to have pictures of your child, so I think I had pictures of him and me together." When I asked another mother if she ever shares her photo album with anyone, she responded confidently: "Yes, with anyone who wants to see it. In fact, I want to show it to everyone and say 'this is my daughter'." Understanding the many dimensions of this "showing off" for parents bereaved by a neonatal death today requires a certain focus on the media technologies now involved in EOL photography. My findings indicate that my participants were not primarily interested in simply communicating the existence of their newborn, as early writing on EOL photography might have suggested through its focus on memento-making. Instead, it seems there is a relation between the narrative capacities of prolific digital images and the parents' ability to show people their EOL images in order to share their own story from the NICU and more extensive details from

their newborn's life and death. Again, I am not suggesting digital technology *causes* these story-telling desires, but rather that the technology materializes these desires within socioculutral practices. I consider two such practices below, which are the sharing of the printed or digital photos in person and the circulation of digital images on social media.

ii) "I'll always bring the pictures with me to share with them, because it's easier for me to remember things when I have the pictures to go through it"

Because digital photography allows for so many frames to be snapped, it facilitates a more narrative style of photography that feels more like a story than the monument of one frame. As shown in Chapter 5, photographic moments can be embedded within the gestures, movements and interactions that make up parenting and construct the narrative of the baby's life and death and the parents' lived experiences within the NICU. It cannot be assumed that the sadness of having a newborn die means that parents will not want to remember or communicate the many moments that make up their experience. In introducing her photo album to me in our interview, one mother expressed how important the photos were in capturing these moments, no matter how hard they were to live:

> You are so devastated, your senses are all over the place, yet you are so focused. I remember each minute, but more I remember [my husband's] eyes, the look, feelings… than actual physicality of the moment. There are a couple of pictures that really get that out. That is why photography in all this is important.

Both the parents' own stories and the stories of their newborns are intertwined in the narrative they construct through their EOL images.

Because almost all of my participants had selected images to arrange in a printed or digital album, our conversations around sharing the photos often related to sharing these albums specifically. Although digital albums were stored on the cellphones or laptops by these same participants for easy viewing, many of them said they went out of their way to bring printed albums to share in various social meetings with friends. A few of the parents specified that they would only do this with "close" friends, indicating an intimacy that dictated their comfort level with sharing. One of the only negative experiences that was recounted about sharing the photos was a mother who had shown them to wider acquaintances in her religious community: "After some people saw the pictures, they were like 'It's good that he passed away, otherwise he would have lived a life where he would have suffered'…which I agree with to be honest with you, but it's kind of hurtful when you hear that just after your baby passes away." It was also the "close" friends as well that were more likely to ask to see the photos, versus more extended social peers who typically would not. One mother's experience with this was as follows: "My closest friends are like 'Let me see a picture. So Cute!'… I think only about four or five people asked…. girls, really close friends, but from the rest there was no asking." One mother specified that she would wait to see if her friends "were interested" in her son's story before she offered to share the photos. Another mother mentioned that her sharing depended on friends' "interest" as well, saying:

I have a lot of friends that want to hear his story and I'll always bring the

> pictures with me to share with them because it's easier for me to remember things when I have the pictures to go through it. I bring it along with me. A few times I've done it where I've just brought it to show people.

This same mother had also thoughtfully framed her son's funeral card with one of his EOL photos to keep at her desk at work:

> I guess I put the funeral card there too so people would see 'oh, he's also not there anymore'. Do you know what I mean? I just wanted to share him with people and I wanted to talk about him. That was my thinking of having the photographs… I guess I wanted people to kind of see it and maybe question it so I could have a way to talk about him. I use pictures that way.

Here we see the mother prompting a conversation about her son through the photos in a social space and, in conjunction with her other response just above, also focusing on telling a story more than simply validating her son's existence. Her language of "using the pictures" again returns us to the notion of the photos as tools. Another example she provided in how she "used" the photos was telling her story to acquaintances who knew she had been pregnant but might not know of the loss:

> I refused to go to the dentist for so long because I have a really close relationship with my dentist and the staff because they've known me since I was little and so they were all excited when I was pregnant and so after he'd passed away I didn't even know if they had known. So I kept putting it off… then finally I decided to go and brought [this album] with me and I was able to sit down with one of the hygienists and I went through the pictures with her and

was able to tell the story.

Another mother shared what she considered to be the experience of people being "pretty positive," saying "they want to hear the story. There are some that just can't handle that. It's too much for them. But most people like hearing about it. Like seeing the pictures." When parents talked about people being interested in seeing their photos, what was always attached to that interest was "hearing the story," as if the value of the photographs was in their narrative and the story-telling interaction. I want to expand on this notion of "sitting down" with someone to "[go] through the pictures" and "tell the story" in relation to the digital technologies with which parents could circulate the EOL photographs without immediate contact—mainly, through social media.

iii) "I don't want them to have that image of my son"

Having their EOL photos as digital files allowed families to email pictures from the NICU to their friends and family who were eager to see the newborn but were not able to visit in the hospital or who lived abroad. It also allowed the parents to have the images accessible on their cellphone or laptop to show friends immediately after their time in the NICU, which was helpful since it often took at least a month or much more before they were able to get their albums and scrapbooks completed to share. None of the participants I spoke to posted any of their EOL images to web memorials or support groups, though half of them did post at least one or more EOL image to their social media page (Facebook specifically). The parents' experience with deciding to share any EOL images online was markedly different than their experience with sharing photos in

person. For one, those who shared the photos were very specific about which images to post and which to not, whereas they tended to share all of their photos when in an album. Returning to the theme of "tubes and wires" reported in Chapter 4 and 5, parents were particularly careful around sharing images that involved extensive medical equipment, using words like "hard," "difficult," "hurtful," and "scary" to describe the images. One mother acknowledged: "She was beautiful for us, but to show it to other people… It's scary…Yes, it can be scary for some people." Another mother who chose to post on Facebook used similar language around the photos being "scary" in explaining how selective she was about this process. Even though she has "lots of stuff on Facebook" she still waited until she had more photos to choose from before sharing anything. Pointing to the first photos in her album of her son who was recently born with large hematomas on his head,[21] she said: "these were the first pictures of him and that's pretty scary to see. I guess it was hard for me to post something like this." When she thought about it further, she came to the realization that the way her son looked wasn't "scary" or "shocking" to her, but might be for her social circle:

> I guess it was for the public to see. You don't want the first viewing of your child on social media to be this picture of him with tubes coming out of everything and no clothes. He looked very sick in those first pictures. I think being able to have him in clothes, he just looked better.

When asked about how people reacted to the photos she recounted a positive experience, but seemed to relate it to the fact that she had waited to post these later

[21] The hematomas appeared as dark, swollen masses on the baby's head caused by the collection of blood.

images:

> Everyone was just so supportive. So many saying 'oh, he's beautiful'… I think people had been wanting to see him for so long and I just wasn't posting any pictures until I guess I felt there was a picture of him that was more of an accurate representation of him. I found that all the tubes and wires were frightening. He looked good here. He was wearing clothes. To me, it felt more comfortable posting something like that.

Another father also expressed his "discomfort" with sharing photos of his daughter that he thought captured her critical illness:

> Even when you take her off all those things and you look at her, she doesn't quite look like a normal baby… I guess I don't want people seeing that. It hurts you know. You want your child to be beautiful. I love my daughter, but when I look at the pictures of her, it hurts. It hurts hard. It's easier to have a foot mold or a hand mold that captures here, but it… It captures the best of her. It's… I don't want people to see.

It is interesting how both participants above talk about the images in terms of being a "more accurate representation" or "capturing the best" of their children. While this does certainly relate to the visual aspects of critical illness that would be visible through such things as bruising, the baby's small size, deformity, wires around the body, discoloured skin, and so on, it is also worth considering the language parents used that points more to a tactile experience than simply a visual one. The language of "difficult" and "hard" images versus the more "comfortable" feeling of a "good" picture

taps into a lived experience of the photos beyond visual perception. Further, two of the mothers used the language of "protection" when talking about their decision not to share certain photos, as one said: "I think I'm just being an over-protective mother. I don't want people to see him like that." There is a sense of standing between the newborn and the people who might see the images, as well as an active component to the "seeing." Just as my findings around photography in the NICU showed how the parents experienced the photography as a relationship with the person holding the camera, these further findings suggest they also experience the photo-objects as a relationship both between them and the viewer, as well as between the newborn and the viewer. Within the NICU, the photography was carried out predominantly by very close family or friends or care-givers who had taken this "journey" with them and whose priority had been shown to include the well-being of the newborn. Likewise, choosing specific friends and family to "sit down with" to see the photos and tell the story seemed to carry the same experiences of care and support as the photography itself. Circulating these "precious" EOL images online without the opportunity to control exactly who was seeing the images or how they would make sense of the images, however, carried with it a certain discomfort or anxiety. In explaining why they did not want to share certain images online, some parents used language of "privacy" or the images being too "personal." For example, one mother who chose not to post on social media replied: "I don't know, but to me, posting anything on Facebook, it's just not for me. It's just too private. It's hard for me to view them, never mind putting them out for all 200 friends of Facebook. It's just disturbing to me." She continued: "I would never. I

don't even have Facebook or anything like that. To me, those pictures are sacred. They are sacred to me and my immediate family.*"* When I asked another participant about social media he replied with similar phrasing, saying "I would never": "Something about that really doesn't sit well with me. It's so personal. I don't want just anyone looking at pictures of [my daughter]." In working through these responses, the photos that were described as "private" or "personal" were often also described as "difficult" or "hard," as if the photos that were appropriate to circulate should be easy, "happy," "living," or "normal," as opposed to communicating the newborn's critical illness or imminent death. One mother's response summed up this sentiment quite clearly:

> Sometimes I see friends who have lost a sister or brother (but when they were older) and they'll post a picture of them and say 'oh this would've been their 20th birthday'… and I just kind of feel like social media… it's just too private for me, like 'oh this is a party we did at work, or this is that or a happy thing,' but I just, I don't… I think for a lot of parents whose child has died they're biggest fear is that they'll be forgotten. And the first year everyone calls on his birthday… and the second year a couple of people call, and the third year maybe two people call… as time goes by I do feel like people will forget, but I don't feel like posting pictures on Facebook is the idea either.

What seemed to be missing in the social media platform was the important component of "story telling" that appeared across so many of the interviews. Touching on this, one mother shared her experiences that informed her decision not to post images on social media versus her experience with sharing the photos in person:

> I didn't want to post any pictures with so many tubes. I wasn't ready to share it with the world. I was only ready to share with my close family. Other people who came over did see the album. My mom I think… because she had quite a few pictures through email… she did share with some of her friends and family members not via email, but just whoever came over she would show it to them on the computer.

When asked how people received the photos in person, she continued:

> You can see a lot of wires and tubes coming out of him, so they were sympathetic, empathetic. Sometimes they were like 'Oh my God, he seems so tiny. There are so many things attached to him.' A lot of people would comment on his face (like, he's really cute. He's really tiny. He looks like [my husband]. It was okay.

Although in both cases her photos include images of her son with "a lot of wires and tubes," it is only in person that she controlled exactly who saw the photos and the interaction between her, them and the images. The response of another mother might provide some insight into wanting to share in person more so than online as well:

> I think it's when I can share the pictures with people in person I am able to talk more and talk about his story, whereas when I'm on Facebook, it's not the same because not everyone knows every single detail that we went through with him. They just know the little snippets and updates. If they messaged me privately I would share information with them, but other than that, they are just seeing the little snippets like he doesn't have his breathing tube in. So they don't actually

> know what's gone on, but they know he doesn't have his breathing tube in. When I'm sitting down and sharing photos, I'm able to tell and they can ask more questions and I'm there to answer. I prefer sitting down with someone and talking personally.

This response shows that she was not necessarily trying to censor the image of her son with the breathing tube in order to make this detail disappear, but rather that she wanted to control the other person's understanding of what it meant to have the tube in, to have the breathing tube gone and all of the details in between that made up her son's life and her own experience. Without these details the EOL photos were reduced to images to be viewed, perhaps to be judged, to be seen floating down a social media news feed with vacation photos. The images then became as banal as the platform through which they were circulating. Just as the one mother used the language of being too "sacred" to post on social medida, another father felt the same:

> I don't know how to put it, but to me it just… "cheapen" isn't the right word, but it loses value. For me, this is something special. This whole journey is so personally painful that it is something I only share with a very select few because I know that they care and that it matters. I don't know how to put it. In social media, it loses value. It's there for the masses to see. I don't know. There is no personal connection through. For me this is a narrative… it is a story.

It is equally important to point out that despite the complicated nature of sharing photos online, the parents who did post images reported it as a "positive experience," as one mother termed it. None of the parents had any outright negative experiences, except

one who recalled an acquaintance posting "congratulations" on a photo of her with the baby, not realizing that the baby had died. Although she understood "the person didn't intend it at all," it still "stuck out" for her as a "negative experience." Overall, however, this same mother had felt confident in posting images online, saying:

> I felt comfortable with it. I was glad I was able to. It was easier for me then emailing a bunch of photos separately. I just posted them in one place and a lot of people could see them. I was comfortable with it. I wanted people to see my daughter. I wanted to share that.

What made her experience positive was that it was "nice to get feedback" and "they would say 'this is my favorite photo' or 'she's beautiful', and so on." Experiencing people's comments, questions and attention on the photos as "positive" aligned with other parents as well, both sharing the photos in person and online. One participant explained: "I felt more connected and supported by other people when they would comment or say something." The language of "connection" and "support" sounds like the same language used to describe the feeling of having the nurses or family offer to take photos in the NICU. There are two points I want to make around this observation in the section below, turning to a significant theme I have identified as 'emotional labour.'

iii) "But some of them can't, they can't look at it, it's too close to home"

What stood out across the interviews was the sense that the participants were often comforting other people instead of receiving comfort themselves. There was a certain

level of work the parents seemed to do around balancing their own desire to share their story with other people's inability to "handle" the sadness or fear around the newborn's death; in other words, the parents had to adhere to certain sociocultural boundaries around the visibility of the newborn's death-in-birth. At least three of the parents even took time to tell me in conversation after the interviews that they hoped hearing all of their stories in this research would not make me anxious about having children of my own; I was amazed and touched that they were concerned for my comfort as a researcher after hearing their stories and coming to understand all that they and been through.

In some cases anecdotes of this work would surface in the interviews unrelated to the photography, as it did for mother who explained how much thought she and her husband had put in to answering the common question 'how many children do you have?' It was very important to them to not answer "one," since this would account for her surviving daughter but not for her son who had died. Part of the couple's wrestling with this social scenario was that "hiding" their son's existence was hurtful and strange. At the same time, she didn't want to answer, "I have two, but one is dead" for this reason:

> Because that always makes the other person feel so uncomfortable and it makes them totally freak out and they don't know what to do and then they always give you this look like 'awww'… It's a horrible look. So now instead of saying that, I just say 'My daughter is 7 or my daughter is 6' or whatever it is, that way I'm not acknowledging that [our son] was there, but I'm making them not feel

uncomfortable.

Participants also mentioned having to console other people through the experience, as this mother remembered doing at her daughter's ceremony of life: "People were crying on our shoulders. At that moment, people were telling me 'Oh my God, we are the ones who are supposed to be holding you and you are the ones holding us'." She recognized people's sadness positively as a show of "a lot of compassion and lots of love for us" which was incredibly important to her and her husband. Another father also appreciated people's compassion, but found it a lot to handle:

> My first days back at work, my office felt more like a receiving line than a place of work. I'd have to leave every day. They were so patient and so supportive and so wonderful with me… past a certain point, everyone was so well meaning and so well intended, but it just becomes emotionally exhausting.

I noted the language of what people "intended" here that sounds similar to the mother I mentioned in the subsection above who also recognized that her friend's comment on her Facebook photo was not "intended" to upset her. It seemed generally accepted that people were not thoughtless or malicious, but simply did not know how to socially handle the death of a newborn. From there, it could be assumed that people would certainly not know how to handle photographs of a dying or dead baby. One mother succinctly provided her opinion on this idea: "It is representing death and people are fearing death."

It was apparent through the interviews that the participants' lack of negative experience around sharing the photos related to the amount of labour the parents

performed in not mentioning the death, not sharing the photos or in curating the images—in making certain "cuts" to return to Kember and Zylinska's language—so they would not be as "hard," "difficult" or "scary" for people to see. One couple that had not shared many of their photos at all with others talked about this with a focus on two important things. One was concern for the people looking at the pictures. The mother began: "We haven't shared much of the photographs… definitely not from [the hospital]. You don't want people falling into depression when they see them. The words are hard enough." She went on to say, "We don't show it because people cried so much. They feel so much. If they would physically see, I think for some of them it would be devastating." Lastly, she concluded:

> People were sad enough, they didn't need to see the whole truth. They have it in front of them, so they don't need to see it. It's more to spare them as well as to keep [baby] in the most beautiful, physical form in their minds because not many people had seen her.

In all of these responses the mother is evoking the photographs as force, their physicality, their potential to devastate, their presentation of a "whole truth" that words alone might not uphold. For her husband, he considered all of this "part of [other people's] problems. It's not my problem." His concern was not for other people, but centred squarely on protecting his daughter:

> For me, it's more like… I didn't want to show her because of her also. Even though she passed away, it doesn't matter… I couldn't show her body like this because it wasn't her anymore. Like [my wife] said, her soul wasn't there

anymore… And also the ceremony and everything we were doing, it was also not only for us or for other people, but for her… to kind of giver her respect.

While all of the participants' emotional labour seemed to successfully foreclose any majorly hurtful incidents as far as comments on the photos, what came into view was that for a lot of the parents the hurt they experienced in social situations often came out of an omission more than an act: Having people simply pretend the photos were not present or that the newborn had never been born. This materialized in birthdays or death anniversaries that were never marked, counting the parents' children without including their deceased child in the number, seeing the parent months later and not acknowledging that anything had happened, never reaching out to the parent during what seemed like an endless stay in the NICU, giving no comments on a "favourite" Facebook picture, or never asking to see any photos of the newborn as one likely would when welcoming a new baby who was not critically ill. We see these moments in one mother's reflections on attempting to share her professional EOL photos:

> When I got the [professional] pictures, they were so beautiful. And there was a video with a song… so where I work we're a small family-run company… and people wanted to see it and so I showed it to one of my colleagues who's a good friend and he was just like, he tried to do it on mute and he was like I can't, I can't do this'… Even now four years later, my family will be like 'oh do you have pictures' and I'll be like 'Oh, look at [the photographer's] pictures, she's amazing, this is what she took, and then here's some happier pictures from later on', all this kind of stuff. But some of them can't, they can't look at it, it's too

close to home or it makes them think 'oh my God what's going to happen to my own kids.'

When discussing people's reactions to the photos of her son that are all over her home, she concluded: "I think they were just really freaked out, and if they see it in the house they'll just pretend it's not there."

I propose the (in)visibility around EOL photography that parents experience in their wider social circles ought to be contextualized within the broader (in)visibility of death-in-birth that I touched on in the first chapter of this dissertation. That is, their experiences resonate with existing sociocultural research that suggests reproductive loss faces a "social silence" and a "culturally sanctioned nonexistence" (Layne, 2003, p. 69). I further contend the lived experience of silence that bereaved parents have expressed in my and other clinical and sociocultural research should not be isolated as an interpersonal issue to be shouldered by individual families, but rather understood as a matter of reproductive justice. In terms of the sociocultural status of reproductive loss, however, I am hesitant to repeat the narrative of absolute invisibility without accounting for the strategic *visibilities* of these phenomena as well, how death-in-birth is made visible, made present, made felt. I argue reproductive loss is not simply unspoken or invisible, but has been discursively produced in "biogenetic capitalism" (Parisi, 2004; Braidotti, 2011) as a risk to be avoided, a psychological stress to be controlled, a medical event to be managed, and a population issue to be regulated within a vast network of power/knowledge that constructs optimal ways of being a pregnant body, a grieving parent, an unborn subject, a dead body, a lost connection. An analysis of EOL

photography must not be based on a "repressive hypothesis" (Foucault, 1978) that only identifies the invisibilities and silences of biomedical reproduction. A fruitful analysis must also identify what *is* seen, said and made sensible, and how photographic and biomedical subjects are produced out of these conditions. I will not explore these political—indeed these *bio*political—dimensions more thoroughly within the parameters of this dissertation, but have written about these ideas elsewhere and will continue to develop them in ongoing projects.[22] With these critical questions in mind, I see my research on EOL photography in dialogue with the growing number of scholars exploring governmentality and "the politics of life itself" (Rose, 2001) in terms of pregnancy, childbirth and fetal becomings (Deutscher, 2010; Stormer, 2010; Fordyce & Maraesa, 2012; Murphy, 2012; Murray & Vanderwees, 2013), while expanding the conversation to include scholars interested in the politics of grief, mourning and death (Butler, 2006; Braidotti, 2010; Rentschler, 2011). There is much more to be revealed about EOL photography in connection with these areas of interest that could not be made visible within the scope of this dissertation; I look forward to forging these connections in future work.

[22] For an example of my work on these ideas see Martel, S.L. (2014). Biopower and Reproductive Loss: Speaking Risk, Silencing Death-in-Birth. *Cultural Studies*, 28(2), 327-345

7. CONCLUDING THOUGHTS: EOL PHOTOGRAPHY AND PALLIATIVE SPACE-TIME AS INTERVENTION INTO BIOMEDICAL LIFE AND DEATH

"[Space] is never finished; never closed. Perhaps we could imagine space as a simultaneity of stories-so-far." (Massey, 2005, p.9)

In summarizing the main findings reported in this dissertation, I begin with a return to the NICU. In Chapter 4 I illustrated the biomedical roots of neonatology as an intensely technologized space developed out of a mobilization of resources around a highly specialized medical knowledge. The NICU is not a background to the experiences that have been presented in this dissertation, but a material-discursive space-time producing the "neonate" as a critically ill subject in need of technoscientific intervention, the "bereaved parent" as a subject in need of psychosocial support, and the "nurse" as a professional care-provider who is responsible for clinically and emotionally managing the end of life. The participants' reflections painted the phenomenological details of this space, describing a disorienting sense of "shock," "chaos," "rushing," "devastation," and simply not knowing what the future would hold for their critically ill newborn. Despite these overwhelming qualities that were felt especially upon entry into the NICU, the participants also described a sense of the hospital coming to feel like "home," a "familiar" space in which many of them formed "special relationships" and "connections" with the staff. Of the myriad healthcare staff with whom families would have interacted, the nurses in particular emerged in the findings as important figures responsible for the parents not only feeling like their newborn was receiving the best "medical care," but that the families themselves were receiving the best "human care." This "human care" is enacted through the nurses' emotional labour, which has been

institutionally recognized and structured within healthcare discourse and consequent training as "relationship-based care" or "family-centered care." A key component of this emotional labour is the encouragement and facilitation of EOL photography by nurses, which registers with the families as a gesture of "support," evoking the sense of having the nurses' photographic attention hold the parents up in a time when there were a lot of difficult choices and circumstances weighing them down.

A central finding from the research is that the "support" offered to parents via EOL photography in the NICU functions within a complex spatio-temporal relation. On one hand, the nurses draw the parents' attention to their newborns' immediate life-story as well as to the parents' life-story *as* parents. In this way the camera is called upon in the NICU as a technology of presence and proximity, materializing the *now* of the parents time with their newborn and the *here* of the parents care for the newborns through contact, closeness and interaction. Parents experience the EOL photography as "time" spent with their newborn or in "doing things" as a family, the vital meaning of which was articulated by the parents as profoundly important. On the other hand, EOL photography also brings the parents' attention beyond their immediate and critical situation; it promises a series of images that meaningfully mediate the parents' lived experience in the NICU with their lived experience in a different time and place, the latter of which would be missing the physical presence of their child. In these terms, the EOL photographs are re-presentations of the newborn in their parents' ongoing lives, not symbolic texts but chiasmic events. These expressions, as vital communication, reveal the photos bringing the parents into being just as the parents bring the photos into

being, as fleshy subjects and material objects sharing a lifeword. As Kaja Silverman says in iterating photography as a "reproductive" medium that is "radically anti-Cartesian": "It shows us that there really is a world, that it wants to be seen by us, and that it exceeds our capacity to know it."[23]

We must also consider the photography itself as inter-action in this lifeworld, which is also beyond an act of representation in any kind of flat sense of the term. As Olin says: "photographic gestures indicate that photographic practices do more than merely represent the world. Gestures turn photographs into presences that populate the world like people and act within it to connect people" (Olin, 2011, p. 14). Phenomenologically speaking, I believe this conception of re-presentation and photographic gesture more accurately captures the never-final or never-separate nature of loss, once we think of bereavement as the state of being distant from another body that we desire to have close. The function of EOL photography in the capacities I have just outlined is not intrinsic to camera technology, but is constructed through the nurses' intentions to foster certain relations between themselves, the parents and the newborns. This intention is shared with the parents, as the families participated in the photography and actively shaped their stay in the NICU space-time through these photographic mediations.

Digital photography's technical ability for fluid photographic gesture, extensive image capture and mobile image sharing plays an important role in EOL photography moving from film-based memento-creation to digital story-telling. Digital photography

[23] This quotation is from an excerpt of Silverman's forthcoming book *The Miracle of Analogy* (Stanford University Press, 2014), made available here: wnonsite.org/feature/the-miracle-of-analogy

allows families to construct more detailed narratives across a wider duration of time and in more intricate ways of using the NICU space for their intimate interactions. As the findings indicate, this photo-based story-telling is a crucial process that brings a livingness to the newborn and to the family as the story is never finished; it is a process of becoming because it is a process of meaning-making, which can never be sufficiently understood as an immutable memorial.

I see EOL photography as an intervention into the way in which biomedicine as an apparatus rationalizes, abstracts and reduces living and dying bodies to physiological successes or failures. Murray (2012) has proposed that Husserl's concepts of the lived-body and the life-world (both of which Merleau-Ponty adapted within his own existential philosophy) might help us counter biomedicine's "rational ethic," which otherwise ignores the "phenomenological dimensions of health and illness" (p. 289). Murray refers to Husserl's work on distinguishing "bodies conceived reductively as *Körper* in the geometric material sense," versus "the body as *Leib*… the 'lived-body', a body that is situated in the life-world (*Lebenswelt*), a bodily life in which bodies coexist through empathy in meaningful community with others, and in intimate proximity with the world" (p. 290). Based on my research, I put forward the argument that the practice of EOL photography, as a collaboration between care-providers and families, is a shared effort to conceive the newly born but critically ill body as *Leib*, as the lived-body, as Merleau-Ponty's body-subject; this is a response to the technoscientific structures in the biomedical space that otherwise produces the neonate as *Körper*. Drawing on the photographic trope in the work of Judith Butler regarding the politics of grief, we might

say EOL photography is a practice of "framing." Butler introduces her investigation into "framing" with this account:

> The frames through which we apprehend or, indeed, fail to apprehend the lives of others as lost or injured (lose-able or injurable) are politically saturated. They are themselves operation of power. They do not unilaterally decide the conditions of appearance but their aim is nevertheless to delimit the sphere of appearance itself. On the other hand, the problem is ontological, since the question at issue is: *What is a life?* The "being" of life is itself constituted through selective means; as a result, we cannot refer to this "being" outside of the operations of power, and we must make more precise the specific mechanisms of power through which life is produced. (2009, p. 1)

With Butler's passage in mind, we can think of EOL photography both as a frame as well as an attempt to build a new frame, one in which the critically ill newborns are socioculturally recognized as living and as becoming, not only as dying subjects. The digital story-telling that families enact is a process of becoming-*Leib*, as well as it is a strategy within the struggle to make unborn-just-born life "grievable" (Butler) by making it visible, countering the ambiguity of death-in-birth in contemporary biogenetic capitalism.

Throughout this dissertation I have referred to EOL photography as an intervention into biomedical space-time. But how might we conceive the space-time re-constructed by EOL photography? By way of concluding, I put forward the term *palliative space-time* as a way of thinking through the way in which nurses and families

act together to resist the rigid structures, the technological distance, the overwhelming tempo, the isolating space, and the administrative demands of critical care—which, by all means, are techniques needed to keep vulnerable bodies alive. Palliative space-time is an experience of presence, focus, living attention, connection, acceptance, and closeness; I believe it is palliative space-time that is being fostered through the many ongoing efforts to provide families holistic care throughout pediatric and neonatal end-of-life and palliative care (Malone, 2003; Lindsay, Cross & Ives-Baine, 2012; Ives-Baine et al., 2012; Ringham, 2012; Widger, 2012). I hope the phenomenological analysis I have conducted in this study on EOL photography contributes helpful insight for future efforts in this regard.

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